EQUITY IN END OF LIFE CARE

A case study of heart failure

Thesis submitted in accordance with the requirements of the
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by
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BOXES, FIGURES AND TABLES

ABBREVIATIONS

GP	General practitioner
NHS	National Health Service
NHSE	National Health Service Executive
UPA	Under privileged area
WHO	World Health Organisation

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DECLARATION

The data presented in this thesis were collected and assimilated by the author during her tenure in the Department of Public Health, University of Liverpool, as a clinical lecturer in public health.

The work contained herein is entirely that of the author unless otherwise stated. The idea for the qualitative study was that of the author, and she wrote the research proposal to obtain funding to support a research associate and associated study costs. All data collection and analysis were done by the author, with support from the research assistant.

ABSTRACT

The United Kingdom National Health Service was founded in 1948 to provide equitable health care from 'cradle to grave'. This thesis focuses on the end of life, when it is especially important that services are available to all, without reference to geography, diagnosis, socio-economic status or ethnic origin. This is a challenge for the health service; the proportion of elderly people in society is growing, new specialist services have emerged, and the range of care options is wide.

The overall aim of this thesis is to contribute to the body of knowledge of equity in health care at the end of life. Using heart failure as an example of a terminal illness other than cancer, this thesis will adapt an existing framework for analysis of equity in end of life care relating to the UK National Health Service principles, and use five empirical studies to address specific aspects of the framework. It will investigate inequities in access to or provision of end of life care between two diagnostic groups and draw out the implications for the United Kingdom NHS.

The first study presents an ecological analysis of routine data, which gives an overall picture of the provision of palliative care beds in the UK, and the relation to socio-economic deprivation. The next three studies use linked mortality and health service data from Oxford and Scotland to quantify the contribution of heart failure to overall mortality, and investigate service utilisation by patients with cancer and heart failure in their last year of life. Particular attention is paid to the role of deprivation, and other influences on length of stay in hospital. The last study consists of two chapters based on focus group interviews with a series of doctors in the north west of England. In these, the doctors perceptions of the need for, and their understanding of palliative care for heart failure are explored.

The findings suggest that end of life care in the UK may not be upholding the equitable principles upon which the NHS was founded. NHS patients with diseases other than cancer have substantial contact with health services at the end of their lives, but the pattern of care is influenced by diagnosis and deprivation. Heart failure in particular makes a significant contribution to mortality. The professional carers of

people dying with heart failure have given little time to systematic thought about their palliative care needs. Changes in NHS policy and practice are needed to respond to these issues.

INTRODUCTION

This thesis is concerned with equity and end-of-life care. On their own, both are important factors in the planning and delivery of health care. Together, they present a challenge to health services that touches on fundamental issues of ethics and social justice.

As life expectancies increase in western countries, the proportion of deaths due to chronic disease such as cancer and coronary heart disease, is rising.[1] Such deaths are predictable, and many are likely to need health care at the end of life. For health systems, these demographic changes present a challenge to both the capacity and capability of current services. The provision of *equitable* care for such a substantial proportion of the population is, in particular, an issue that is easily overlooked.

Although people who are labelled as 'terminally ill' have reached the same phase in the life cycle, the dying are far from being a homogeneous group. Even if expected survival is broadly similar, the health and life experiences of dying people are varied. Medical problems, material circumstances and personal resilience are amongst the factors that affect the perceived need for care. In turn, there is little uniformity in the provision of services for the dying. The number of different agencies involved in caring for people at the end of their lives may be large. Appropriate care may incorporate any or all of mainstream health services, social services, charitable providers, private nursing homes and lay carers. What constitutes equitable care for the majority, and who should deliver it, are by no means easy questions. The complexity of possible models of care on offer has grown in recent years, and this complexity also increases the likelihood that the quality and quantity of care will vary from place to place, and person to person. Thus, health care at the end-of-life is an area where the concept of equity may be very difficult to translate into practice.

There are many important issues surrounding end of life care, and it is not possible to investigate all of these within one thesis. I am going to focus on inequities between patients with different diagnoses, and in particular, the experiences of people who do not have cancer. Heart failure will be studied as a condition that typifies the experience of people with chronic progressive diseases.

Focussing on heart failure moves the thesis from the theoretical to the practical, and ensures that this work will have outcomes relevant to the care of patients at a number of different levels. A mixture of methods has been chosen as being appropriate to this subject area. Throughout the thesis, each section may be read independently. Although this means that at times, some arguments are repeated (particularly in the empirical studies) this approach is intended to make the work more accessible.

It is important to note that I started this work from the perspective that palliative care is often done badly in the NHS. This view was based on experience of working within a variety of hospitals and general practices in the UK, and it had found support in work I had conducted for a health authority.[2;3] A service review illustrated that even within the five localities of that one health district, the provision of care varied widely. The role of the charitable sector in particular, was poorly integrated with NHS planning, yet central to the experience of the patient.[4] Research with bereaved carers found that a substantial proportion of people felt that they had been poorly served by their health professionals.[5] Interest in this variation, and the possible inequity in service provision it represented, is behind this thesis.

The hypothesis and approach adopted

The hypothesis underlying this work is that significant inequities exist in end-of-life care in the UK, the nature and extent of which have not been documented. Characterisation and understanding of any such inequities are essential, if they are to be addressed.

This thesis starts by setting out the background of equity in health care, and its relationship to the values and principles of the United Kingdom National Health Service. This provides a framework in which to set the empirical studies that follow. An overview of the literature relating to access to end of life care is presented, along with a short discussion of what quality means in this context. Five empirical studies make up the body of the thesis. Study I is a correlation study, which explores area level deprivation and palliative care bed provision, from routinely available data. The following studies use heart failure as a case study, to ask if palliative care meets the needs of people who do not have cancer. Study II, a descriptive analysis of death certification data from the former Oxford region of the UK, quantifies the strengths and limitations of this source of information. The third study then uses linked mortality and hospital utilisation statistics to compare the bed days used by patients who died from cancer and heart failure. Study IV uses a larger and potentially more informative dataset from Scotland, to explore the differences in resource use between cancer and heart failure patients, and explore the influences on length of stay and the number of admissions. The last study, V, is a focus group study with doctors in the north west of England. This explores their perceptions and understanding of palliative care for heart failure.

BACKGROUND

Palliative and terminal care have been recognised as an important part of UK health care for over forty years, but until recently the end of life has attracted relatively little attention from health services researchers.[6;7] This is not an easy area - practical and ethical challenges are a prominent feature of research with dying patients. People with terminal illness are a potentially vulnerable group,[8] and research ethics committees are rightly sensitive to their well-being when considering applications for research studies. Distress and upset are an inevitable part of the dying process for patient and carer, and researchers may be viewed as an unwelcome intrusion at a difficult time. The physical condition of a patient can prevent them from participating in or completing a research project, and the death of participants before a project is completed is not unknown. It is not surprising, therefore, that much of the evidence base for palliative care is drawn from analyses of routine data, postal surveys, or the use of proxies, such as bereaved carers. Many important aspects of this phase of care, such as symptom control and analgesia, have been investigated using traditional research methods from the biomedical sciences. However, the standard tools such as the randomised controlled trial have had little success in this area,[9] and there is greater acceptance that questions in this field, whether concerning service delivery, or psychological, social and spiritual issues, are often best answered with methods from other paradigms.[10] Qualitative methods in particular, may offer unique insights.

Pressures on existing services

The number of people who may need health and social care at the end of life has risen in recent years. The reasons for this are many. Chronic diseases are responsible for a majority of deaths, giving a more predictable workload in end of life care. Longer life expectancies and the decline of the extended family may mean that more complex health and social support is needed for frail and isolated elderly. At the same time as the demands on services have grown, clinical governance and closer media scrutiny have focussed attention on the quality of care. It seems that the pressure on clinicians to provide uniform, good quality care has never been greater. Yet in this sphere, it is often not clear what constitutes ‘good care’. In the UK, the impact of the restructuring of the health service and changes to the provision of social care on end-of-life care are not yet apparent. Other factors, such as the declining capacity of the private nursing home sector are certainly creating pressures on in-patient beds for older people. Whilst recent initiatives, such as joint assessments for community services between health and social care, may alleviate some of these problems, the overall picture is of a service that is struggling to meet existing demand.[11] End of life care is, therefore, of great interest to policy makers. It touches everyone at some point in their lives, it is intensely political, and the costs may be substantial.

The policy context

The National Health Service in the UK was established in 1948 to provide healthcare for all, based on need, and not the ability to pay. Whilst it has continued on this basis ever since, the social and geographical inequalities in health that were, in part, a stimulus for the founding of the NHS, have not entirely disappeared. The first major publication to document inequalities was The Black Report, published in 1980.[12] Largely ignored by the incumbent Conservative administration, it played a key role in stimulating extensive documentation of health inequalities and inequities over the next few decades. However, it was not until the Labour party came to power in 1997 that inequalities in health became a target for government action. Since then, there have been a number of policy documents that establish equity as an underlying principle to health service strategy, and attempt to explicitly tackle health inequalities.

A number of NHS strategy documents that are relevant to end-of-life care show that importance is also placed on the provision of equitable care. The National Service Framework for Older People, for example, suggests that care should be ‘ person centred, rooting out age discrimination’, and that ‘all services should reflect the diversity of the population which they serve.’[13] In 2000, the National Service Framework for coronary heart disease directed health authorities to produce equity profiles for coronary heart disease. It also implicitly addresses diagnostic inequities in service provision, by suggesting that consideration should be given to the palliative care needs of patients with heart failure.[14] The Cancer Plan details increased spending ‘to end inequalities in access to specialist palliative care,’ and mentions socially deprived and ethnic minority groups in particular.[15] Thus the policy context is supportive of moves to ensure that services are equitable. What is missing is the definition of practical steps by which health care services can respond. Through identification and exploration of diagnostic inequities in end of life care this thesis will begin to respond to this gap.

The historical focus of palliative care is changing

The worldwide hospice movement has its origins in the UK, and much of its growth and success can be attributed to the early efforts of one woman, Dame Ciceley Saunders. As a social worker, and later a doctor, she was a powerful advocate for terminally ill patients, whose medical management lacked the holistic approach and emphasis on symptom control that characterises modern palliative care.[16] Ciceley Saunders was closely involved with the opening of the first hospice in 1967, St Christopher's in Hackney. Following this, many other in-patient units for the dying were established throughout the UK, providing care predominantly for cancer patients with challenging physical and psychosocial problems.

Although the early pioneers had no specific intention to exclude patients with other diseases from holistic, structured end-of-life care, terminal care is strongly associated with cancer. When the hospice movement started, the problems of pain control and communication were perceived as being particularly challenging with cancer patients. Specialist palliative care is, like the hospice movement before it, a small scale operation, and coping with the number of cancer patients who require palliative care consumes available resources. Extending specialist palliative care beyond cancer has been debated extensively.[17] More and more research evidence is being presented to illustrate the difficulties experienced by dying patients within other groups, such as those with neurological diseases, chronic obstructive pulmonary disease and heart failure[18-20] Responsibility for their care lies with the relevant hospital specialists and the primary health care team. The advice of experts in palliative care may be sought, but it is less usual for them to be involved. This leaves a potential gap in the terminal care of people with diseases other than cancer, as palliative care skills may not be widely available in every medical speciality.

After the opening of the first hospice in 1967, it was 15 years before the first piece of NHS guidance relating to palliative care appeared. Known as 'The Wilkes Report', this investigation by a working group of a Standing Medical Advisory Committee identified education, training and support of hospital and community staff as priorities for development in palliative care.[21] Palliative medicine was subsequently recognised as a separate specialty in 1987, and went on to be acknowledged as an important contribution to cancer care in the 'Calman-Hine' reports on the reorganisation of cancer services in the mid 1990s.[22] Official guidance from the department of health encouraged UK health authorities to fund palliative cancer care, and then develop purchasing strategies that would encompass all diseases.[23;24] Although the latter should have incorporated care for heart failure patients, the first specific guidance to appear was the coronary heart disease National Service Framework in 2000.[14] This recommends that 'the benefits of palliative care should be considered' for patients with heart failure. Thus there is little official support for excluding patients with other diagnoses from specialist palliative care. In practice, however, although a few interested doctors have developed expertise in treating non-cancer patients with specific conditions, the majority of specialist palliative care is still delivered to cancer patients.[25]

Heart failure – clinical and epidemiological features

Heart failure has been chosen in this thesis as an example of a chronic progressive terminal disease. Typical patients with heart failure are in their seventh or eighth decade. Former smokers, they may have suffered a myocardial infarction a few years earlier. The patient with heart failure will almost certainly have other medical problems, typically chronic obstructive pulmonary disease or diabetes. Without medication, they will be tired all the time, short of breath, and complaining of swollen extremities. Night time may be a particular concern, as they cannot lie flat to sleep, and may wake fighting for breath. As the condition worsens, these patients may find that they can only walk a few steps, and need oxygen at home to help their breathing. Depression is common. Acute attacks of breathlessness and chest pain may result in frequent admissions to hospital, and the chance that they will die during one of these is high.

Heart failure is a clinical syndrome, caused by left ventricular dysfunction. The symptoms result from complex circulatory and neurohumoral responses to the impaired cardiac contractility, and they may vary widely. There is no one accepted definition of heart failure, but all standard definitions encompass some objective evidence of cardiac dysfunction with a range of clinical symptoms.[26] The major aetiological factor in the development of heart failure is coronary artery disease, though hypertension, valvular disease, alcohol abuse or viral infections may also all be responsible.

It is clear that heart failure is relatively common, and that it is largely a disease of older age groups. The detailed epidemiology of heart failure remains unclear, in part due to the absence of an accepted definition for heart failure, and poor diagnostic accuracy. Various methods have been used to assess the prevalence of heart failure, including examination,[27;28] self or interviewer administered questionnaires, scrutiny of medical notes,[29;30] use of medications,[31] or the results of tests such as echocardiograms.

In primary care populations, estimates of prevalence in all age groups range between 0.4-1.5%.[26;29;30] Over the age of 65 years most studies suggest a prevalence of around 8-9% in this age group, but this ranges up to 19%.[32] Population based studies have shown an even wider range of prevalence rates; between 1.6 and 5.5% in men, and 1.4 and 4.3% in women.[32;33] These differences will reflect variation in the method of ascertainment, the population chosen (hospital based or general population), the diagnostic and definitional criteria used in the study, as well as the underlying true differences in prevalence rates.

However it is measured, the prevalence of heart failure is rising.[34;35] More people survive acute myocardial infarctions than was the case, and many of them will go on to develop heart failure in months or years. Similarly, the prognosis of other chronic cardiac states has improved with better treatments and management. A proportion of these patients will also develop heart failure.

The advent of new diagnostic techniques, such as echocardiography was expected to clarify the epidemiology of heart failure. However, it has, instead, shown that left ventricular dysfunction may exist without any signs or symptoms.[33] (This is termed ‘asymptomatic left ventricular dysfunction’, and not heart failure). Recent trials that have demonstrated a beneficial effect of treating asymptomatic left ventricular dysfunction with ACE inhibitors,[36] have raised the possibility that case finding is a worthwhile exercise. Another important development in heart failure care has been the identification of B-type natriuretic peptide, which is released from the ventricles of the heart in response to haemodynamic stress. This is a relatively sensitive and specific marker for heart failure, and is being employed for rapid diagnosis.[37]

Definitions of specialist palliative care and the palliative care approach.

Palliative care, and specialist palliative care will be referred to throughout this work, using the definitions provided by the National Council for Hospice and Specialist Palliative Care Services. These have also been adopted by the UK NHS Executive.[38]

Box 1 Specialist palliative care definition

'Specialist palliative care is accepted to be the active total care of patients with progressive, far advanced disease and limited prognosis and their families, by a multi-professional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support, and will involve practitioners with a broad mix of skills, including medical and nursing care, social work, pastoral/spiritual care, physiotherapy, occupational therapy, pharmacy and related specialties.[24;38]

A distinction is made between specialist services delivered by trained personnel, and a 'palliative care approach,' which emphasises holistic care of the patient, and should be part of all clinical practice.

The 'terminal' phase of illness is arbitrarily defined as being the last 12 months of life.[38] Palliative care, however, aims to provide for the patient throughout their illness, from the time of diagnosis. In practice, many referrals to palliative care teams are made when the patient is near to death and the specialists face the challenge of persuading patients and primary care colleagues to their belief that earlier intervention would be beneficial.

Concepts of Equity

All definitions and understanding of equity are built on a value framework, even it this is not always made explicit. An explicit framework or context within which to set decisions is attractive as a means to avoid the potential inconsistencies, prejudices and oversights that influence decision-making. Although there are theories from moral philosophy that could be used to inform judgements about equity, the human rights perspective on health comes closest to providing a consensus approach. This has its roots in the Universal Declaration of Human Rights from 1948, which stated that 'everyone has the right to a standard of living adequate for health and well being of himself and his family…'.[39] A human rights approach to health puts people at the centre of any developments, promotes equality and equal opportunities for all to fulfil their potentials. This is reflected in the constitution of the World Health Organisation (WHO) and has been adopted by many non-governmental organisations working in health development. It is also implicit in much of the work of the NHS.

The human rights approach also underlies the definition of equity adopted by the WHO. This proposes that to achieve 'equity in health', everyone should have a fair opportunity to attain their health potential.[40] Differences in health that were unfair, unjust and avoidable could then be termed inequities. This definition has the advantage of being relatively simple, but obtaining agreement on which inequalities can be judged avoidable, unnecessary and unfair, is less easy.[41] Much hinges on what are considered to be the causes of health differences and what can be done about them. If one takes the view that inequalities in health that are attributable to environmental, social, political and economic policy differences are amenable to intervention, then differences due to these causes are all unnecessary and avoidable, and hence may be judged to be inequities. Braveman offers a definition of equity in health that lends itself more easily to measurement. For her, equity is represented by the absence of systematic disparities in health between social groups who have different levels of underlying social disadvantage.[42] This definition is sufficiently broad to encompass absolute and relative deprivation, and social disadvantage arising from characteristics other than wealth, such as power or prestige. But although a focus on social disadvantage may well capture the majority of important inequities in health, it does not prioritise potentially important differences between males and females, or ethnic groups, for example. However equity in health is defined, it is important to note that equitable access to public resources and social justice are central to achieving the right to health. Equity in health *care* is only one path towards that state.

Meeting health care needs equitably should include all aspects of health care, including financing, funding, access, responsiveness and quality, macro and micro-management and decision making of the health care system.[43] The principle of equity in health care should also recognise the range of different needs that people have. This is articulated in the distinction drawn by health economists between horizontal and vertical equity – the former referring to equal access for people with equal needs, and the latter, appropriately different access for people with differing needs.[44] Equitable health care is generally understood to be available to people according to some definition of need for treatment, and not on factors that are irrelevant to that need.[45]

The theory of equitable health care has found support in health systems around the world and much has been written about it. In reality, it has proved difficult to translate into policies and practice. Through a review of the published literature and other sources, the next section looks at equity in terms of the NHS principles, and relates them to end of life care. (Methods for obtaining the literature are found in Appendix 1). The aim of what follows is to provide an overview of what is known about how equitable end of life care is in the UK NHS.

Literature Review: Equity, end of life care and the NHS

The National Health Service was founded after the Second World War to provide equitable health care to UK residents. It was based on principles that were reiterated by the Royal Commission of 1979, and again in the policy documents of the incoming Labour administration after 1997. The NHS was to be a universal service, without fees, geographically equitable, providing a high standard of care for all.[46] More than half a century later, the NHS is still providing universal coverage. Attempts to introduce aspects of the market into health care have largely failed, and suggestions of privatisation attract little public support. In spirit, the NHS holds on to its founding ideals. Whether individual services are able to deliver the reality of equitable care is less certain.

Changes in health care since the NHS began have been rapid and radical. Many technological advances such as scans and surgical techniques had not been dreamt of in 1948, and penicillin was not in widespread use. The 1911 National Insurance Act had initiated employer based insurance for poor working men, which allowed them access to primary care. Hospital services were a mixture of voluntary and local authority institutions. Paying for services had been a fact of life for the majority of the population. Palliative care was the province of nurses and the old style hospices; with sympathy and prayer substituting for the pharmacological and psychological expertise of present day specialists. The question posed in this section, is to what extent has end of life care maintained equitable principles, in the face of rapidly developing services? To address this, the NHS principles most relevant to end of life care are selected, and relevant evidence from published literature and other sources are reviewed.

- **A service for all**

After 1948, UK citizens had a right to health care, with the same service provided for rich and poor alike. The absence of any checks on eligibility was considered to be particularly important, and to this day, there is no requirement to prove citizenship or residency when a patient presents as an emergency at a UK hospital. Such easy access to health care is a fundamental part of providing equitable health services.

Access to treatment in the UK aims to be available according to some definition of need, irrespective of issues such as ability to pay, age or gender.

The measurement of access is not straightforward and utilisation of care is often employed as a convenient proxy. It is far easier to measure who, or how many people used a health service, than it is to know who *could* have used it. Similarly, it is difficult to quantify the benefits that may accrue when a person knows that a service is available to them, even if they do not choose to use it. Differing educational levels, cultural and social experiences will mean that equal access will not necessarily lead to equal utilisation. Some services will be less acceptable and accessible to certain people compared with others. Interpretation of utilisation is also not without problems, as people should also be able to exercise their rights not to access health care, if they so choose. These are general limitations of research into access to health care, but they may be particularly important in end of life care, when a person's psychological well-being is so important. The knowledge that the district nurse is a telephone call away may make the difference between coping at home and admission to long term care, for example.

A service for all diagnoses?

The most obvious way in which end of life care is not provided for all is in terms of diagnosis. For many years end of life care in the UK has been synonymous with cancer care. Current services for the dying are modelled around cancer patients' needs, although cancer accounts for only around one quarter of the deaths in the UK. People with other diseases also have predictable deaths with a terminal period, but appropriate awareness and expertise of terminal care may not be available to them. Disease specific services such as specialist nurses, for example, are rarely directed at the end of life, whereas specialist end of life services are largely provided for cancer patients. To put this in perspective, in 1999/2000 only 4.8% of referrals to specialist palliative care were for non-cancer diagnoses.[25] A person dying with heart failure may receive care from the district nurse, for example, but there is no equivalent to the more specialised advice or night time care that Macmillan and Marie Curie nurses provide for cancer patients.

Other patient characteristics may serve to exclude them from end of life care. The pattern of chronic diseases is different in different ethnic groups, and the social structures and cultural expectations all mean that current services may not be meeting these differing needs. Gender also contributes to the definition of a person's need for care. Women live longer than men, and experience more chronic illness as a result. In old age, they are more likely to be carers, and to live alone. Their need for psychological and social support may be great.

A service for all social groups?

There are many reasons why the distribution of health care needs at the end of life might vary with socio-economic status. The uneven distribution of illness in society is well documented. Whether individual measures of socio-economic status such as occupation or income are used, or area based indices derived from census data, the poor in society are consistently shown to experience more chronic illness and die at a younger age. All cause standardised mortality ratios are higher in the poorer districts in England. Mortality from coronary heart disease and lung cancer are highest in the lowest socio-economic groups, for example.[47] As well as experiencing more disease, the poor also have greater severity of illness.[48;49] Although deprivation will exert a direct effect,[50-53] access to health services is also thought to be a factor.[54] Some sections of society; minority ethnic groups, as well as the poor and elderly may experience problems in obtaining access to health care.[54] These factors, with more severe illness and death at a younger age, are likely to increase the need for care at the end of life amongst poorer sections of society. An equitable health service would reflect these greater needs with a greater concentration of health services in poorer areas.

In the UK, there has been little research into the relationship between socio-economic status and access to, or outcomes of palliative care. Cartwright's 1973 study is one of the few larger scale works to address this issue.[55] Cartwright and colleagues examined the lives and care of a random sample of 960 people in 12 areas of Britain. They focused on the needs for medical, nursing and personal care, and the ways and extent to which these were met. Bereaved carers were identified through death registration, and interviewed at home by specially trained researchers. Although it produced valuable new insights into the plight of the dying, this study detected few social class differences.

There were no differences in reported symptoms or restrictions or the type of help people needed. A higher proportion of people in social class I died in private nursing homes compared with classes IV and V. The reverse was true for deaths in hospital. The number of informal carers involved was similar in all classes, though the patterns were different, with the working class relying more on children, and the middle classes on friends and neighbours. A clear gradient in housing conditions was apparent. The follow up study published in 1992 showed that more affluent people had a better quality of life and less financial hardship before death (n=639), even though they died at older ages.[56]

Cartwright's study relied entirely on information gathered after death, from someone who lived with or cared for the person who died. This technique is often used in palliative care research for pragmatic reasons, but the validity of information obtained from proxy respondents is debated. The studies that compare relative or carer views after death with those of the patient before they died fail to provide definitive answers, as most have methodological drawbacks. All are of small size[57-59] – with one of the best known having a sample size of six.[60] The time periods that patients and carers are asked about are different in some of the studies, and validity of the measuring instruments is unknown in most cases. Despite these limitations, they all demonstrate a tendency for relatives to report symptoms as being more severe than the patients did. Agreement between responses relating to subjective symptoms such as pain, or anxiety was, in general, more limited than that relating to the provision and use of services. Addington-Hall and McPherson present evidence from studies assessing concurrent views of patients and relatives, arguing that if there is no agreement in such studies, retrospective reports are unlikely to be valid.[61] This analysis describes a similar picture, supporting the use of proxy views in service use and evaluation.

Other investigators have considered the influence of socio-economic status in the context of broader studies. A review of the medical records of people who died of cancer in one health district over a year (n=521) failed to demonstrate any association between the occupational social class of cancer patients who accessed specialist services before death and those who did not.[62] Similarly, Hinton reported that social class had no bearing on whether cancer patients were admitted to in-patient care from a home care service over two years in London (n=415).[63] However, supporting data were not presented in this paper, so it is not clear how social class was measured, and whether it was an individual or area based measure.

Palliative care for the majority of people who die in the UK is provided by mainstream health and social services. It is estimated that the specialist palliative care services saw 16,890 outpatients in 1999-2000, the latest year for which data are available. A total of 41,466 were newly admitted to hospice in that time period.[64] In comparison to the one in four of the population who die with cancer each year, this represents a minority of patients. In addition, solutions for end of life care for non-cancer diagnoses may be difficult to distinguish from good chronic disease management. Ensuring that access to mainstream care is fair is therefore crucial to equitable end of life care. The way in which patients access care at this time will reflect patterns of behaviour that have developed from previous encounters, and this may mean that important health needs at the end of life are not met.

In the NHS and a few other health systems, the primary care doctor is the gatekeeper to more specialist services, and a central figure in facilitating access to care. This is most clearly seen in countries such as the UK or the Netherlands, which operate parallel private and public insurance systems, with a prominent role for the GP in the latter. In Holland, the strong gate-keeping role of the GP is evident in the reduced use of secondary care amongst the publicly insured.[65] Thus, access to primary care has great potential to both reduce and create inequities in health care. However, the decision to consult a primary care physician will be influenced by many factors, ranging from the patient's own health beliefs and expectations to the availability of alternative forms of care.

Referral to secondary care is an important outcome of consultation with primary care practitioners and people living in socio-economically deprived areas or working in manual occupations are less likely to be referred to secondary care by their general practitioners in the UK.[66-69] A similar picture is apparent in other health systems, including Canada.[70]

The availability of hospital services in relation to need has received less attention from researchers. Kesimaki and colleagues have looked at socio-economic differences in all hospital care across the whole of Finland, controlling for patterns of mortality and prevalence of self-perceived illness.[71;72] The trend to high hospital use in lower socio-economic groups was mirrored by social gradients in mortality and morbidity, suggesting equity in treatment. Accounting for differences in the severity of illness is also important, as otherwise aggregate data may conceal important differences in the process and outcomes of care. For example, less affluent patients may be seen later in their illness, with consequent reduced chance of curative care. This was illustrated by a study of patients with glaucoma at three London hospitals. People who presented late for care, and were therefore at greater risk of blindness, tended to live in more deprived areas and to be of lower occupational social class than other patients.[73]

Ischaemic heart disease, responsible for one in four deaths in developed countries, is now recognised as a disease of poverty rather than affluence. Socioeconomic inequalities in cardiovascular disease are apparent in most industrialised countries, with commonly the lower social classes and less well educated being more severely affected.[74] Similar social patterning should therefore be expected in the use of services. Re-vascularisation procedures for ischaemic heart disease have been the subject of a large number of research studies, and the results are remarkably consistent. It does not appear to matter which country is being studied, or the method used to determine socio-economic disadvantage, the more deprived people in societies are less likely to gain access to investigation (angiography) and re-vascularisation procedures (percutaneous transluminal angioplasty or coronary artery bypass grafting).[67;71;75-78] Adjustment for need, using either mortality rates[71;75] or community surveys of symptom prevalence[76] support the idea that patients were not being prioritised for admission on the basis of their clinical condition. The more deprived also waited longer for admission to hospital.[79]

In contrast to the low rates of routine referral to specialist care, poorer people have high rates of emergency hospitalisations and admissions. This is neatly illustrated by a study of hospital admissions within one English health authority area. Deprivation at the GP practice level was positively correlated with emergency, but not routine admissions.[80] Similar patterns of hospital use have been described in Canada,[81] the USA[82] and Finland.[72]

A service for all religions?

The UK hospice movement was built with Christian foundations on the good will of volunteers and charitable giving. It is inevitable that helpers with time to spare, usually women, were drawn from the higher social classes. The perceived 'twin set and pearls' image of the hospice has been proposed as a barrier to patients from different social backgrounds, though this has never been investigated in a research setting. Similarly, many hospices have an overt religious affiliation. Some such as St Joseph's or St Christopher's are named after prominent figures in the Christian tradition; others were staffed by people in religious orders. This may have deterred patients who hold other beliefs from seeking admission, either because they chose not to, or because they believed themselves not to be eligible.

A service for all minority ethnic groups?

Many cancers have lower prevalence in minority ethnic groups, and illnesses such as coronary heart disease may be more important causes of death in some ethnic groups. Assessing the need for, and access to specialist palliative care services is therefore difficult and there is relatively little research in this area. This omission was recognised by practitioners and policy makers in the United Kingdom, and the National Council for Hospice and Specialist Palliative Care Services commissioned a study in 1995 into the palliative care needs of black and minority ethnic groups. The Department of Health and the Cancer Relief Macmillan Fund provided funding, and the researchers identified three areas with a high proportion of minority ethnic residents for further study, in Birmingham, Leicester and London. Strategies, policies and guidelines were scrutinised, and interviews conducted with specialist palliative care providers, general practitioners and staff of community and voluntary groups working with black and Asian patients. This research was concerned with developing recommendations for the provision of appropriate services in the UK, and used routine mortality data to estimate the number of deaths in white, black and Asian ethnic groups, in order to judge the adequacy of service provision. Palliative care was more likely to be provided by hospitals and community based services rather than specialist palliative care. Potential barriers identified by the interviewees included the emphasis on cancer, and a lack of cultural sensitivity.[83;84]

Most UK research into palliative care for minority ethnic groups is of small scale, and uses the less robust methods available to health services researchers, such as interviews with carers and doctors, and analysis of hospice activity. Dewi Rees is generally acknowledged as the author of the first such investigation.[85] He described socio-demographic and clinical characteristics of people who had been born outside the UK, and were admitted to a Birmingham hospice between 1979 and 1985. His methods combined prospective data collection with retrospective note review. Of the 2,605 patients receiving care, 74 (0.02%) had been born outside the UK and were classified as immigrant, compared to 10.2% of the city population who had been born outside the UK. Compared to the indigenous patient population, Asian males were older, and Asian females younger. Although few immigrants were admitted to hospice, they were more likely to gain access once they had been referred. A similar study fifteen years later in Derby described small numbers of patients from minority ethnic groups admitted to hospice (15/1035 (1.5%) admissions over one year). Here, there were few referrals from the community, and the majority of patients were referred from the hospital palliative care teams.[86]

People in ethnic minority groups are likely to develop terminal illness at a younger age than white British,[87] so the failure to age-standardise the data may underestimate the potential hospice patient population. Interviews with bereaved carers have suggested possible barriers to specialist services for minority ethnic patient groups that might explain these apparently low referral rates. Koffman and Higginson interviewed 50 black Caribbean and 50 white bereaved carers in London.[88] They found that fewer blacks accessed specialist services, and the black carers were generally less satisfied with health care received, particularly from primary care. However, in common with many similar studies, the participation rate was low (45-47%), and it is difficult to know how representative the interviewees were of their communities. A smaller project with 18 bereaved carers of Bangladeshi patients referred to an East London palliative care team identified problems with communication, particularly the use of translators, and disagreement between carers and professionals on the desirability of disclosing information to patients.[89] In addition, it was clear that many people preferred to go to their country of origin during a terminal illness or failing that, for burial.

Semi-structured interviews with 15 consultants and 12 GPs in Birmingham considered barriers to palliative care for minority ethnic groups.[90] Many doctors felt that patients from black and Asian ethnic groups preferred to use family care, and that hospice care would not accommodate their cultural traditions. They also commented that patients were not aware of what hospice services had to offer. Language barriers and a paucity of appropriate information were also said to be important factors. Overall, minority groups used less day care and inpatient hospice care, and more home care services than the majority white population. Over eighteen months, around 8.5% (144/1681) of referrals to hospice were drawn from the minority groups, although they make up a higher proportion of the population in the west midlands.

Compared to the population as a whole, a lower proportion of people from minority ethnic groups access specialist palliative care. This may reflect a lower incidence of cancer in non-white ethnic groups, or it may reflect the presence of barriers in access to care. The data are of poor quality, and age-standardised admission rates would shed light on the possibility of inequities in access to hospice. However, it seems likely that there are significant socio-cultural barriers for people from ethnic minorities, and untested assumptions amongst medical staff.

A service for all ages?

Longer life expectancies mean that many people anticipate a healthy retirement and old age. Ensuring that health and social care are available to the elderly on the same basis as their younger peers has important organisational and financial implications for a health system. Making treatment decisions on the basis of age, loosely termed 'ageism' is widely criticised as an inequitable approach.[91] Patient and carer preferences, current health status, availability of treatment and the chances of success are all factors that health professionals will include in their assessment. A patient's age will influence many of these factors, and there are objective, physiological reasons why some treatments should be used with caution in elderly patients. It may be particularly difficult for health professionals to separate these justifiable considerations from ageist prejudice.

Most of us in western countries will die in old age, a high proportion will have predictable deaths from chronic disease. This suggests that the majority of people requiring end of life care will be elderly, yet the figures for utilisation of specialist palliative care services suggest that in-patients tend to be younger than the average for all cancer patients.[64] Older patients must therefore be receiving non-specialist palliative care from hospital and community services. Whilst services designed for older patients may be sympathetic to their wishes, it is also possible that they may adopt general attitudes that make interventions less likely. This is particularly likely in the hospital setting, where certain procedures or referrals may not be the norm for patients on geriatric wards, for example. On the other hand, services that cater for patients across the age spectrum, such as the medical subspecialties of oncology or renal medicine, implicit rationing by age may occur when doctors are treating a certain number of patients with limited resources.

Much of the evidence in this area comes from large North American studies. The most significant of these is the SUPPORT study; a large multi-centre project conducted in the United States between 1989 and 1994. This research is set in a system without universal health care coverage, where there are explicit financial barriers to health care access. Professional attitudes, patient preferences, and societal norms may differ markedly from the UK. However, the data on patient preferences and the content of care may have relevance to the UK.

The SUPPORT study involved 9105 seriously ill patients in five North American hospitals. Extensive data were gathered on clinical conditions, as well as care preferences, decision-making and outcomes. A review of the outputs from this study suggested that although older patients preferred less aggressive care, when this was adjusted for, along with prognoses, older people were treated less aggressively.[92-94] As the authors comment, this either means that younger patients underwent excessive, ineffective treatments, or, that useful therapies were withheld from older patients. Patients over 65 years of age did have more discussions about care than their older peers; they also spent shorter periods in hospital and died sooner. Analysis of data from the entire Medicare population confirmed these findings from the SUPPORT study.[95] In 1992, major procedures were seen to be used with caution in the last year of life, and for the very old. Only eight per cent of those patients who died underwent a procedure in their final year.

The National Mortality Followback Studies, also in the United States, described shorter hospital stays for the very elderly over 85 years.[96] These surveys consist of probability samples of all deaths in the United States in 1986 and 1993, with response rates from next of kin of 90%, and 88% for people aged over 65. Quality of life in the last year of life was seen to improve between these two surveys, but other measures of activities of daily living, cognitive function and overall sickness score did not change.

A preference for symptomatic or 'comfort care' over life saving measures was also seen in the Hospitalized Elderly Longitudinal Project (HELP). This was a prospective study of 417 patients aged over 80 years, who died within one year of admission to one of four American teaching hospitals.[97] In the last month of life, three out of five expressed a wish not to be resuscitated. Overall, quality of life was rated as poor and functional impairments significant.

It seems that no researchers have set out to investigate access to specialist end of life care for the elderly. The North American data reviewed here describes the care received when patients have already accessed the health system. The more elderly stay for shorter periods and are treated less aggressively, which may be appropriate. However, the possibility that this hides significant inequities in access to care cannot be excluded. This is an area that merits further research.

- **Sharing financial costs and free at the point of use**

All care at the end of life care in the UK is supported by sharing costs between a wider population. Risks are pooled, and care is free at the point of use. Health care in general practice, mainstream hospitals or NHS hospices is funded by direct taxation. The rest is provided by charitable giving, where costs are shared between the charity and the donors. A number of large charities, such as Macmillan, Marie Curie and Sue Ryder have established in-patient units and community teams. Usually, the proportion of costs provided by the NHS is subject to local negotiation. Guidance from the NHSE in 1995 suggested that NHS district health authorities should work towards contributing 50% of the cost of palliative care services.[22] Currently, the proportion of NHS funding has varied between 30 and 100%. It is not clear how the funding is distributed at a national level, and there has been no recent review.

Charitable providers have been behind the establishment of palliative care in the UK, allowing the rapid development of services. With the freedom to innovate, unconstrained by having to provide for all, they can create exemplary or special services if there is a local drive to do so. There is a potential conflict between the need for services in poor localities, and an obligation to reward communities where giving is the greatest. This may, to some extent explain the location of hospices in more affluent suburbs. There is certainly intense competition for finite charitable monies, a situation exacerbated by the establishment of the national lottery.

The freedom of charitably funded services is a double edged sword, as they are not constrained by local NHS plans or palliative care strategies. Smaller charities in particular, may prefer to support new buildings, as they provide a visible focus for a fund raising campaign. One hospice in a northern city expanded its in-patient buildings, for example when the local NHS was attempting to expand palliative care in the home.[2] This lack of accountability is a challenge for local health service planners, but it also thwarts NHS attempts to ensure that end of life care is a service for all.

- **A comprehensive service**

NHS care extends from 'cradle to grave', and within this, it was Bevan's intention that all forms of health care and promotion should be provided. This includes preventative care, as well as treatment services, including rehabilitation and chronic care. Whilst Bevan showed laudable foresight in describing a comprehensive service, it does not translate easily to end of life care. The question of 'what is palliative care' is difficult enough to answer. Defining *comprehensive* palliative care requires a judgement to be made on what ought to be available, and what priority should be placed on this service over any other.

Specialist palliative care has already been defined as the active total care of patients with progressive, far advanced disease and limited prognosis and their families, by a multi-professional team who have undergone recognised specialist palliative care training. However, most patients will receive all the care they need at the end of their lives from their GPs and district nurses. Ability to pay is relevant only when the patient or carers perceive the need for services not provided under a 'comprehensive' NHS. Some may seek out complementary therapies or less conventional forms of symptom control, but most of these extra therapies are provided by private practitioners on a fee for service basis. Home nursing is a good example where the amount of care provided may be less than the family would want. Funds to pay for extra nights from an agency nurse, may enable a relative to stay at home, for example. There may be many extra costs incurred when someone is ill; special food, extra laundry, travel to hospital all put a price on caring. Socio-economic status or earning power will be an important factor in the decision to give up work when someone falls ill, and this may define how much lay care is provided. Thus end of life care may be 'free' in the UK, but the patients' experiences may relate closely to their economic circumstances.

In practice, it is more usual for a decent minimum level of health care provision to be defined. This is seen most often in countries without universal health care coverage, such as the United States. There, the safety net is set at a low level, and the weight of evidence for inequalities in access to health care is great. Worse health care for poorer people and ethnic minorities are a particular problem.[98] In France, the minimum coverage has recently been increased. The rapid rise in health care utilisation, and presentation of problems that had been neglected over many years because of an inability to fund necessary care, illustrate the difficult of achieving a 'decent minimum.' In most systems, the safety net will fund acute, life saving services, whereas the less urgent forms of care that are needed at the end of life are much less likely to be included. In the USA, hospice care (which refers to end of life care, not necessarily as an in-patient) has been included in the Medicaid scheme, after much debate. It is likely that any care provided as a 'decent minimum' will leave aspects of comprehensive palliative care to be funded in other ways, including private purchase. In the UK NHS, there has been no tradition of defining the services available. There are signs that this is beginning to change, with the advent of National Service Frameworks and involvement of non statutory bodies such as the Hospice Information Service.

- **A geographically equitable service**

With the foundation of the NHS, it was expected that everyone should be within acceptable travelling distance (and time) of services. Specialist palliative care was not available at the start of the NHS, and services have subsequently developed at different rates in different areas. Many of the advocates of palliative care have an almost religious zeal for spreading the palliative care message, and this is one of the reasons that it has influenced the inherently conservative medical world. It also means that the existence of services may depend on persuasive individuals with skills in lobbying and negotiation. As already touched upon, charitable funding has allowed a rapid growth of palliative cancer care, with nurses being the mainstay of most services. Macmillan Cancer Relief is one of the largest charities in the UK. It provides funding to pump-prime posts for specialist nurses who work closely with NHS hospital or primary care teams, advising on symptom control and the availability of other relevant services. Since 1975, when the first Macmillan nurse was appointed, they have grown in number to 1700.[99] Marie Curie Cancer Care is the largest charitable provider of hands-on nursing care in patients' homes.[100] Currently, they provide over 1.1 million hours of care every year in the UK, usually with half of the cost provided by the NHS and half by Marie Curie.

In-patient facilities have grown at a similar rate. There are now 3029 beds in 208 units in the UK, with 334 home-care and 221 hospital-support teams. Day-care is available in 243 units.[101] Fifty-six (27%)of the 208 palliative care in-patient units are NHS managed, representing 596 (19.8%) of the total 3029 palliative care beds. The proportion of beds in the UK that are NHS managed (and funded) ranges between 2.7% and 49.3% per region. In the 1980s, the geographical distribution of specialist palliative care resources was described as inequitable, concentrated in the affluent south east of England.[102] Today, wide inter-regional variation remains. Trent region currently has the fewest beds, at 35.1 beds per million population, whereas at 66.7 beds per million, North West region has the most. However, the distribution of beds shows no apparent relation to the size or density of population. These figures also conceal a wide variation in bed use, with average length of stay ranging between 6.2

and 19.3 days (mean 12.8), and throughput (average number of discharges and deaths per bed) 10.6-46.0, (mean 23.1). So although there are many more facilities than thirty, or even ten years ago, the distribution of resources and variation in service models are still potential sources of inequity for cancer patients.

- **A high standard of care for all**

The NHS was intended to provide the same high standard of care for all. The situation of the early twentieth century, where the poor had different or inferior services was to be replaced with one high standard service for all social groups.

In end of life care, the place where patients with cancer die has been used as a proxy outcome measure for end of life care, with a home death considered a success. Research that has investigated associations between place of death and socio-economic status has produced conflicting results. Studies of routine mortality data have shown that a lower proportion of people resident in deprived areas will die at home from cancer in England and Wales.[103;104] However, when social class was derived from the occupation stated on the death certificate, people with cancer in the upper and lower social classes (I,II,IV,V) were less likely than those in middle groups (III) to die at home in one health authority district in England (n=831).[105] As this study was set in a relatively poor area of South Yorkshire, it is possible that these findings are peculiar to that location.

Primary research using a variety of methods has failed to demonstrate any relationship between patients' social class and their place of death. Both interviews[106] and postal surveys with bereaved carers[107;108] found that social class derived from occupation of the deceased was unrelated to likelihood of home death. However, the response rate achieved by the postal survey of 229 carers from an inner London health district was only 53%.

A similarly conflicting picture is evident in Australia. Residence in less deprived areas,[109;110] having a professional or non-manual occupation and private health insurance[111] have all been shown to be associated with death at home. Other researchers have found no relationship between these factors and place of death.[62;112;113] There are limited data available from North America, but interpretation is complicated by the way in which health care is funded.

Overall, it is difficult to know how to interpret the research on place of death. People's choices are known to change as death approaches, and they will be influenced by a range of factors, including the views of relatives or carers. The carers' ability to cope mentally and physically with a burden of increasing care is usually central to any decisions made. The availability of services and local conventions may also play a part. Socio-economic status will, of course, affect the ability to purchase extra support, such as nursing care or equipment that may enable a person to stay at home. Availability of nutritious food and heating may also influence the place of care The well recognised ability of the better educated to manipulate the health system will also mean that poorer people are disadvantaged. However, the complexity of the situation and its influences mean that the research evidence offered, based on routine data or postal surveys, does little to further our understanding of whether might be an association between social class and place of death.

Improving quality in health services generally has become an important focus for large sections of the health care community. A better experience for the patient is the central goal, but raising quality also attracts support as a means of containing spending on health care and a step towards greater efficiency. In the NHS, quality improvement has been given a boost by the introduction of clinical governance, and a renewed emphasis on good professional practice.[114] Quality should certainly be an essential component of equitable health care – a fair distribution has little meaning if the resources are not of a comparable high standard. However, there are almost as many definitions of quality as there are authors on the subject. (Most are more applicable to health care for an individual, as quality within population health care would need strong emphasis on efficiency and equity, with provision for exceptional individual needs). Some definitions state general principles such as excellence or outcomes achieved,[115] others discuss quality in terms of its component parts, such as access, equity, effectiveness.

Donabedian is responsible for one of the best established definitions, where quality is a function of effectiveness, efficiency, efficacy, acceptability, equity and legitimacy.[116] Such definitions present a complex view of quality that encompasses the perspectives of both providers and users of care, and emphasise the extent to which the concepts of access, equity and quality overlap. For example, Maxwell[117]and Donabedian both define quality with reference to equity. O'Leary[118] and Maxwell include accessibility in their definitions. Thus, accessibility and quality are used to define equity, whilst equity and accessibility define quality. Campbell and colleagues cut through this confusion, and suggest that there are only two essential components of quality; access and effectiveness.[119] They argue that all other aspects may be described within these two components. Quality is then defined as whether an individual can access the health structures and processes of care which they need and whether the care received is effective.

High staff patient ratio, lengthy consultation times and overt emphasis on caring have led to a perception that end of life care is synonymous with high quality. But in the same way that other developments in end of life care tend to be implemented more slowly than technological advances in medicine,[120] formal attempts to categorise or measure quality in end of life care are relatively recent. A number of taxonomies of 'quality end of life care' have been proposed,[121-123] in an effort to simplify and understand this complex area. They are informed by research that has highlighted areas of concern such as symptom control, preparation for death and an holistic approach by health staff.[121] Important differences between the priorities of professionals and patients have been described. For example, patients may place great emphasis on lucidity, whereas doctors are more willing to trade off mental alertness for pain control.[123] The different taxonomies reflect different combinations of patient and provider views. The six best known taxonomies are tabulated (Table 1) below.

Table 1 Taxonomies of ‘Quality in End-of-Life Care’

	AUTHOR (ORGANISATION) OF TAXONOMY					
DOMAINS	**Journal of the American Geriatric Society**[124]	**Institute of Medicine**[125]	**Emmanuel EJ**[126]	**Singer PA**[127]	**Patrick DL**[121]	**Stewart AL**[128]
Overall Quality of Life	√	√	X	X	√	√
Physical Symptoms	√	√	√	√	√	√
Psychological Symptoms	√	√	√	X	X	√
Social Functioning/Relations	√	√	√	√	√	√
Spiritual Well-being	X	√	√	X	√	√
Economic Demands	X	X	√	X	√	√
Control/Autonomy	√	X	√	√	√	√
Advance Planning	√	X	X	X	√	√
Avoiding Prolongation of Life	√	X	X	√	X	√
Family Burden	√	√	X	√	X	√
Patient Satisfaction	X	√	X	X	√	√

Between them, they describe 11 domains relevant to end of life care. Only two domains, physical symptoms and social functioning, occur in every taxonomy. Psychological concerns, spiritual well being, patient satisfaction and the impact on the family are the other domains that contribute to standard definitions of palliative care. In addition, some taxonomies have included the level of control or autonomy retained by the patient, and the existence of advanced planning. The economic demands of dying and avoiding the prolongation of life have also been considered. Only one taxonomy includes all 11 domains.

The chosen domains are a mixture of some issues that can be measured objectively, such as economic demands, with others that require subjective rating scales, such as physical or psychological symptoms. For some domains, a specific scale is unlikely to be available, measurement of the burden placed upon a family by a death, for example. Such heterogeneity is useful to the extent that it reflects the myriad of influences on patients and carers, it but creates a methodological challenge, when aggregating these measures into a single framework.

The frameworks have been criticised for their professional approach, being vague and confined to established rating scales.[129] Such a lack of consensus is unhelpful to practitioners and patients, and it is not surprising that no one taxonomy has been adopted into general usage. In the past, quality of life scales have been developed which allow the participants to choose the domains on which they answer questions.[130] Perhaps this is an approach that could be applied to the construction of a taxonomy, thus avoiding the imposition of a professional view on what is important at the end of life. The taxonomies appear to have limited practical significance, but they do highlight the issues that clinicians, planners or researchers should be considering. For this thesis, they provide a framework to construct the topic guide used in the focus group study (V).

There are a number of practical initiatives in the UK which are working towards definition of quality. Benchmarking and voluntary audit of hospice teams has been coordinated by the Royal Society of Medicine. Recognition of palliative medicine as a speciality and organisation of training are important steps to improving the standard of practice in end of life care.

Summary

One of the major problems facing policy makers is the absence of clear standards against which to assess the outcome of health care provision, and answer the question 'has equity been achieved?'[131] This brief overview has looked at the issue from a different angle, to see if equitable principles are being applied. The current research base does not provide definitive answers, but it does suggest that UK end of life care may not be the comprehensive service for all that it should be. The following empirical studies will contribute to the assessment of the principles of universality, geographical equity and comprehensiveness.

AIMS AND OBJECTIVES

The overall aim of this thesis is to contribute to the body of knowledge of equity in health care at the end of life. Using heart failure as an example of a terminal illness other than cancer, I will answer the following broad aims:

- To review existing evidence for equity in end of life care
- To carry out empirical studies of end of life care for heart failure patients
- To draw out the implications of the findings for end of life care in the United Kingdom NHS, with a particular focus on heart failure

To meet these aims, a literature review and five empirical studies will address the following objectives :

1. To describe the patterns of end of life care for different diagnoses and geographical areas, using published literature relevant to the founding principles of the UK National Health Service as a framework.
2. To investigate the association between area level deprivation and provision of palliative care beds in England and Wales.
3. To describe the contribution of heart failure to overall mortality
4. To characterise the hospital resource use of patients with heart failure and cancer in their last year of life, and to identify influences on length and number of admissions.
5. To examine factors underlying inequities in UK end of life care by identifying and understanding doctors' perceptions of end of life care for non-cancer patients, using heart failure as an example.

EMPIRICAL STUDIES

Study I	**Palliative care beds and social deprivation in England and Wales: A correlation study using routine data**
Study II	**A descriptive analysis of death certification in people with heart failure using data from the former Oxford region UK.**
Study III	**Hospital bed utilisation in the last year of life by patients with cancer and heart failure : A comparative study of routine NHS and mortality data in the former Oxford region UK.**
Study IV	**Use of NHS hospitals in the last year of life- The role of diagnosis and area deprivation. A comparative study of routine data in Scotland**
Study V	**Doctors perceptions and understanding of palliative care for heart failure--A focus group study with consultants and general practitioners in the north west of England**

STUDY I: Palliative care beds and social deprivation in England and Wales: A correlation study using routine data

Introduction

The poor have worse health and die younger,[132] but does the social divide influence the experience of a 'good death'? More extensive provision of specialist palliative care in the affluent south east of England was described in the early 1980s.[102] However, services have expanded rapidly since then, and the 'Cancer Plan' of 2000 commits the NHS to ending inequalities in access to palliative care services.[15] Specialist palliative care has also been criticised for providing services to a privileged minority. There are strong suggestions that the likelihood of dying at home is decreased by living in a socio-economically deprived area, and increased by receiving specialist palliative care.[104] It is possible, therefore, that the provision of palliative care may contribute to social variation in the experience of dying.

The aim of this study is to identify any association between area level deprivation and provision of specialist palliative care in-patient beds for England and Wales in the late 1990s, using routinely available data.

Materials and methods

Data on the number of NHS and non-statutory adult hospice and palliative care beds for each NHS district in 1999 were obtained from the Hospice Information Service.[101] The data are derived from an annual questionnaire survey of all palliative care services, irrespective of their funding source (response rate 70%). Figures for individual units were mapped to health districts by hand, using the postal address. A 'Z score' was calculated to compare the number of beds in each district with the mean for England.

Underpriviledged area (UPA) deprivation scores were obtained for electoral wards in England and Wales, from the University of Manchester Information Service. The underprivileged area score (UPA) is an area-based measure of additional workload or pressure on the services of GPs.[133;134] To construct this score, GPs UK wide were surveyed and asked to give weighting to variables depending on how important they figured in their workload. Eight census variables were normalised, standardised and weighted and then summed to give a score for a geographical area. The 1991 census variables that were used to calculate the UPA scores are shown below, with their weightings.

Table 2 Census variables used to calculate the UPA score

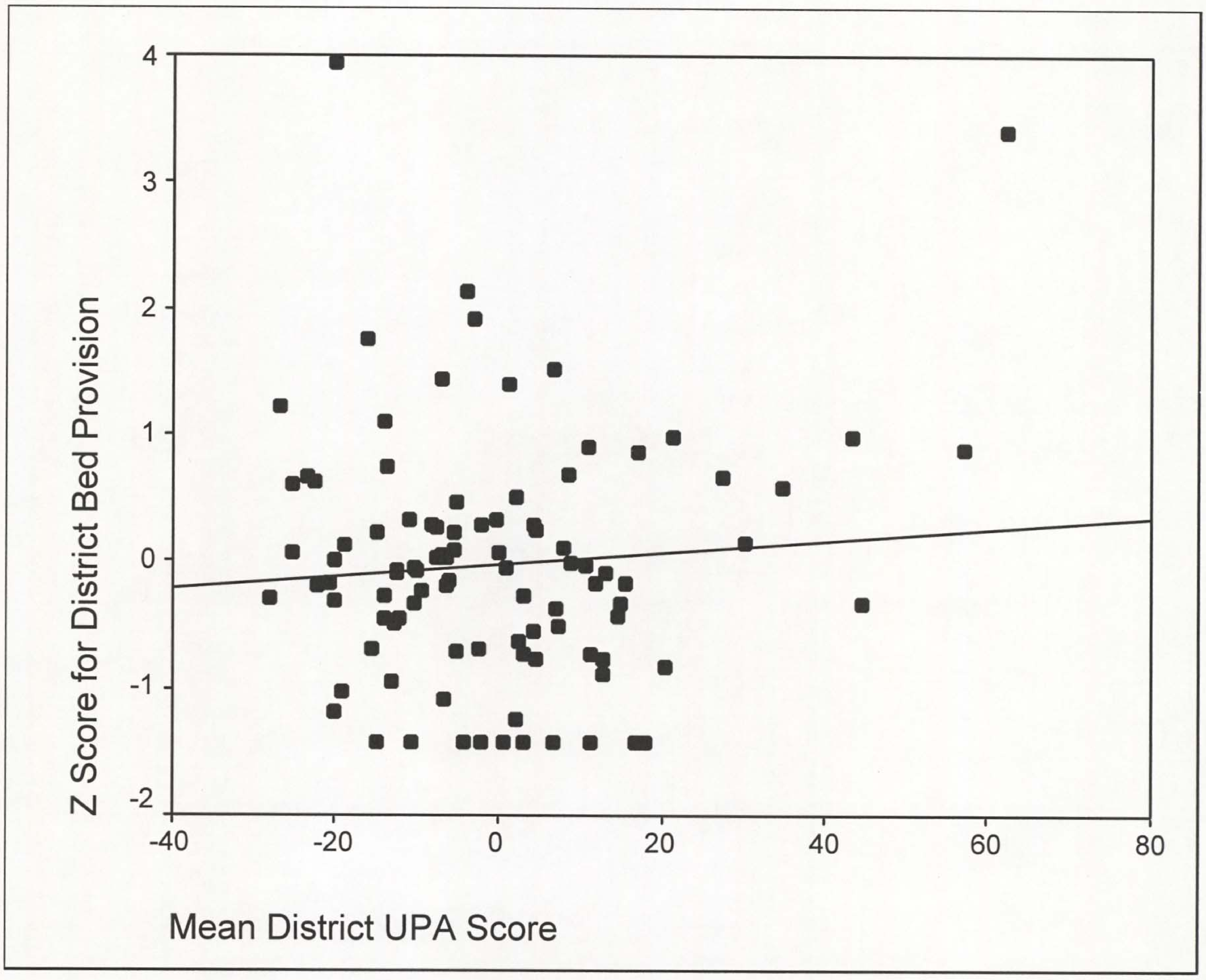
Census variable used in UPA score	Weighting
Elderly living alone	6.62
In one-parent families	3.01
Children under 5 years old	4.64
Social class v (unskilled workers)	3.74
Unemployed (as % of economically active population)	3.34
In overcrowded households	2.88
Have changed house within the last year	2.68
Ethnic Minority: Born in the New Commonwealth or Pakistan	2.50

The UPA and Z scores were plotted against each other and Pearson's correlation coefficient was then calculated to examine the relationship between deprivation and the number of beds.

Results

Provision of palliative care beds by deprivation of area in all 100 English health authorities is shown in Figure 1. The UPA scores were highest (indicating greater deprivation) for districts in North Thames, Northern and Yorkshire and the North West, and lowest in Anglia and Oxford and the South West. Adult bed provision ranged from 35.1 beds per million population in Trent, to 66.7 per million in the North West. In the UK in the year 2000, 56 of the 220 in-patient units were NHS managed, representing 600 (19%) of the total 3207 beds. The proportion of beds in England that were NHS managed ranged between 2% and 37% per region. From Figure 1, the Z scores indicate that there is no relation between provision of beds and deprivation of area as measured by the UPA score (Pearson's correlation coefficient 0.08, p=0.43).

Figure 1 Palliative care bed provision and under-privileged area scores in 100 English health districts, 2000



(Pearsons correlation coefficient 0.08, p=0.43)

Comment

This analysis has shown that the provision of palliative and terminal care beds is not consistently lower in districts with higher levels of deprivation, as measured by UPA score. However, as poverty is associated with greater needs for health care,[54] the absence of an inverse relationship between the number of beds and deprivation score is the significant finding of this study

The implications of these findings are limited. Bed numbers are a relatively crude measure of service provision, and the availability of services in a health district may conceal inequitable distribution at local level. Urban areas, in particular, are likely to confound these results: being associated with both deprivation and high concentrations of facilities. The significance of palliative care beds may also be questioned. As palliative care teams focus increasingly on care in patients' homes, many services choose to maintain fewer specialist inpatient beds. Appropriateness and quality of care are crucial, and bed numbers offer no insight into these aspects of health care. Nevertheless, despite these limitations, staffing levels are closely correlated with the number of beds, and education and diffusion of good practice are important roles for palliative care specialists that are relatively independent of geography. The availability of beds is also an essential prerequisite to receiving in-patient care of any quality.

The UPA score was used in this study because it was available in a format that corresponded with the boundaries of the information on beds. It was developed originally to measure workload in general practice, and the variables listed in Table 2 reflect this. Although it has been used extensively as an area based measure of deprivation, variables such as single parents and children under five are not particularly relevant to this study.

The value of correlation studies is in their ability to generate hypotheses. It is likely that the high proportion of charitable funding for palliative care has allowed greater flexibility for providers, and contributed to the current haphazard distribution of services. Charitable giving is said to be higher in affluent areas, and this may conflict with the greater needs of people who experience deprivation. The combination of the findings of this study and the known socio-economic differences in place of death suggest that the current distribution of facilities and the way in which disadvantaged patients access care should be examined more closely.

This study has illustrated the limitations of data that are available routinely, but not in a format that allows easy analysis. Information on health services provision or the material circumstances of the patients are not sufficiently detailed to allow useful analyses to be performed. The key to ending any inequalities in access to palliative care services is being able to characterise them, and this must lie in better information systems.

STUDY II: A descriptive analysis of death certification in people with heart failure using data from the former Oxford region UK

Introduction

As heart failure becomes an increasingly significant public health problem, the need for good quality descriptive data assumes a greater importance. Information from death certificates has many uses, including assessing the prevalence of heart failure, characterising the demography of patients, reviewing place of death and commenting on health service outcomes. Much of this information is of value in planning health services, and it is therefore crucial that it is accurate as possible.

There has been much confusion over the use of 'heart failure' in certification. The term 'heart failure' may be used to refer to the mode of death, as well as the coronary syndromes. However, description of the mode of death, rather than the cause, is not allowed on death certificates. In addition, there are coding rules which may influence heart failure death statistics. For example, in the UK, heart failure would not be coded as the cause of death if the patient has previously had a myocardial infarction, yet this is a common situation.

In this study, the causes of death were reviewed, for people in the former Oxford region of the UK, whose death certificates mentioned heart failure, either as the underlying or contributory cause of death. **The aim** was to investigate the contribution of heart failure to overall mortality, and give an accurate description of the hidden burden of heart failure, when it is a contributory factor to the death, but not the underlying cause.

Materials and methods

Mortality statistics from the former Oxford region of England were used. This area has a population of 2.5 million and is the only area of England where data on deaths are linked to hospital utilisation. Certificates relating to deaths between 1996 and 1998 were reviewed. From the total population, there were approximately 79,125 deaths in the three year study period. All deaths where heart failure (ICD 9 codes ICD9 425.4, 425.5, 425.9, 428.0, 428.1 and 428.9) was the underlying cause of death were selected. The other causes of death were then noted. Secondly, all deaths were selected where heart failure appeared on the certificate, but was not the underlying cause of death. The underlying causes of death for these people were recorded. The underlying causes of death for people who had heart failure on their certificates are displayed in rank order, and the proportion of deaths that they represent.

Results

Between 1996 and 1998, heart failure was stated as the underlying cause in 1.9 % (1481 deaths) of total deaths. For 1161 (78%) of these cases, other causes of death were given (1852 other causes stated in total, mean number of other causes 1.6 per death). In a further 8.3% (6534) of all deaths, heart failure was given as a contributory cause.

Table 3 shows the other causes of death stated on certificates where heart failure was given as the underlying cause of death. Respiratory infections (404, 27.3% of the 1481 deaths attributed to heart failure) were the single biggest underlying cause of death, followed by chronic obstructive and related respiratory diseases (219 cases,14.8%). The high proportion of deaths attributed to senility (226, 15.3%) reflects the age of patients with heart failure. Cancers were mentioned in only 71 (4.8%) deaths from heart failure, of which 19 were cancer of the prostate. The category ‘other causes’ (9.6% of deaths) combines dermatological, orthopaedic, congenital anomalies and muscular dystrophies. In 80 cases, heart failure was stated as a contributory, as well as the underlying cause of death.

Table 3 Stated causes of death, where heart failure was given as the underlying cause of death on the death certificate, residents of the former Oxford region 1996 - 1998

Other Causes Stated on the Death Certificate	Number	% of other causes stated (1852 other causes stated for 1161 cases. 320 cases had only heart failure on the death certificate)
Respiratory causes, including infections and obstructive airways disease	623	33.64
Senility and other psychiatric conditions	226	12.20
Cardiac causes	222	11.99
Other causes	142	7.67
Renal / urological	139	7.51
Neoplasms	71	3.83
Diabetes mellitus	71	3.83
Cerebrovascular disease	67	3.62
Gastrointestinal disorders	60	3.24
Injuries/ poisonings	55	2.97
Complications of medical care	36	1.94
Peripheral vascular disease	33	1.78
Cerebral degenerations and other neurological disorders	32	1.73
Anaemias and other diseases of the blood	28	1.51
Septicaemia and other infections	23	1.24
Thyroid disease and other endocrine conditions	24	1.30
TOTAL	**1852**	

Table 4 describes the 6534 cases where heart failure was mentioned on the death certificate, but not as underlying cause of death. In more than two thirds of cases (4516, 69%), the underlying cause of death was cardiac related. Within this group, 'other forms of chronic ischaemic heart disease' (2592 cases), and acute myocardial infarction (1082 cases) were the largest subgroups. Respiratory disorders accounted for 868 (13.3%) of the underlying causes of death. Almost half of these (411) were infections of the respiratory tract, 368 chronic obstructive pulmonary disease and related conditions, and 86 other respiratory, which includes the industrial lung diseases and other fibrotic conditions. Cancer was the underlying cause of death in 254 (3.9%) cases. Lung cancer was stated on 42 certificates, prostate cancer 33 and colon 24. No cancer site was specified in a further 24 cases.

Table 4 Causes of death, where heart failure was mentioned on the death certificate, but was NOT the underlying cause for residents of the former Oxford region 1996 - 1998

Underlying Cause of Death	**Number**	**% of total cases with heart failure as a cause of death, but not the underlying cause**
Cardiac Causes	4516	69.12
Respiratory causes, inc. infections and obstructive airways disease	868	13.28
Neoplasms	254	3.89
Cerebrovascular disease	168	2.57
Renal and other urological disorders	144	2.20
Gastrointestinal disorders	127	1.94
Other	98	1.50
Diabetes mellitus	97	1.48
Peripheral vascular disease	96	1.47
Senility and other psychiatric conditions	36	0.55
Thyroid disease and other endocrine conditions	34	0.52
Septicaemia and other infections	30	0.46
Anaemias and other diseases of the blood	30	0.46
Cerebral degenerations and other neurological disorders	27	0.41
Injuries and poisonings	9	0.14
TOTAL	**6534**	

Comment

Heart failure contributed to approximately one in ten deaths. When heart failure was the underlying cause of death, a range of other causes were given on death certificates. However, heart failure was most likely to be mentioned as a cause of death *other than* underlying, in cardiac related deaths.

The proportion of deaths attributed to heart failure as the underlying case (1.9%) is similar the work of Murdoch and colleagues on Scottish deaths (1.5%),[135] though considerably higher than previous estimates for England, of 0.8% of male deaths and 1.5% of female deaths.[136] However, the proportion of deaths in which heart failure was a contributory cause (8.3%), is considerably lower than the equivalent Scottish figure of 14.3%. In Scotland, the deaths attributed to heart failure as underlying cause had no other causes stated on the death certificates. In the former Oxford region, other causes were given for 78% of deaths where heart failure was the underlying cause.

Limitations

Death certification relies on an accurate clinical assessment of the cause of death, or findings from a post-mortem examination; adequate completion of the certificate by the attending physician, and appropriate transcribing and later coding of the information. A great deal has been written about the accuracy of death certification, and it is clear that errors or omissions may occur at every stage of the process.[137] When data from post mortem examinations have been correlated with information on death certificates, major discrepancies have been revealed.[138-140] In this case, it is likely that individual practitioners had different understanding of the use of 'heart failure' in certification. Some of this variation in diagnostic practices or completion of certificates should have been ameliorated in this study by the use of data from one former region. However, the use of 'heart failure' in both underlying and other causes of death does suggest that there may also be inaccuracies in the collation of data.

Implications

If the term 'heart failure' has been used appropriately in death certificates, this study has confirmed that heart failure makes a large contribution to mortality in England. Both cancer and heart failure together were factors in a relatively small proportion of deaths, which is important for the following studies that compare the two groups of patients. It is noteworthy that when heart failure was considered to be the underlying cause of death, the majority of 'other' causes stated were not of cardiac origin. Although this is consistent with a high proportion of people with heart failure having other co-morbid conditions, it also raises the possibility that the mode of death is being described. Many causes of death will precipitate the heart to fail, and all deaths involve it ceasing to pump. Description of the events at the time of death do not contribute to our understanding of the aetiology of cardiac disease, nor do they help in planning for prevention or treatment.

This study has implications for the rest of the thesis, as mortality statistics relating to heart failure deaths will be used in study III and IV. In the next study, I will examine hospital bed use by heart failure patients in their last year of life.

STUDY III: Hospital bed utilisation in the last year of life by patients with cancer and heart failure : A comparative study of routine NHS and mortality data in the former Oxford region UK.

Introduction

In the UK, terminal and palliative health care are virtually synonymous with cancer services. When patients dying with other chronic diseases require in-patient care, there are few alternatives to hospital admission. Consequently, people dying from non-cancer diseases may receive care that is inappropriate[141] and costly. Analysis of trends in Oxford and Australia in the 1980s and 1990s showed that there has been no increase in the time spent in hospital in the last year of life, despite increasing longevity.[142;143] However, no recent studies have investigated acute hospital bed use in the year prior to death by different diagnostic groups. In this study, hospital bed utilisation in the last year of life by patients with heart failure was compared with that of patients with the five most common cancers. The aim was to see if heart failure patients spend as many days in hospital in the last year of life as cancer patients.

Methods

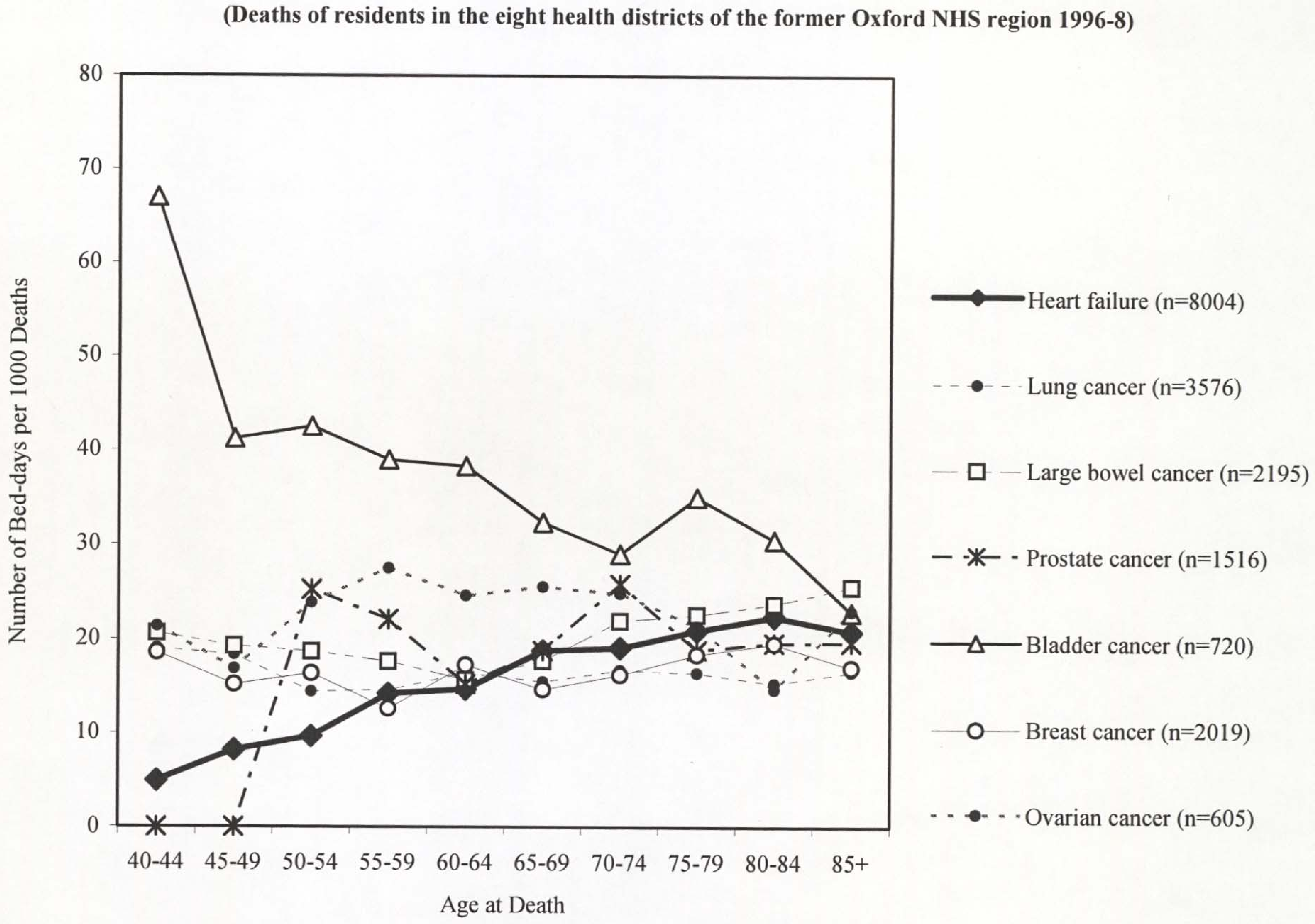
Data were extracted from the Oxford Record Linkage Study, a linked routine database maintained jointly by the NHS and University in Oxford. This related individual hospital inpatient records to death data for the 2.5 million population of eight health districts in the former Oxford region. Data about successive admissions for the same person were also linked, and, since 1979, all causes entered on death certificates were coded.

Admission rates for the final 12 months of life were studied for men and women who died in the three year period 1996-1998. Data were analysed in five year bands for age at death from the following causes: heart failure (ICD9 codes 428.0, 428.1, 428.9, 425.4, 425.5, 425.9), all coronary heart disease (ICD9 codes 410-429), all cancer ICD9 codes 140-208), and the five most common cancers in men and women (lung 162, large bowel 153,154, prostate 185, bladder 188, breast 174, ovary 183).

Results

Cancer was the stated cause of 18,991 deaths, heart failure for 8004 (1497 underlying cause of death (19%), 6507 elsewhere on the death certificate (81%). Heart failure patients accounted for 161,303 bed-days, 45% of the total used by patients with coronary heart disease. This was equivalent to 41% of the total bed-days for cancer patients in this study. Patients with heart failure had a greater average length of stay (13.3 days) than any of the individual cancers, or cancers combined (Range 7.8 ovarian cancer to 11.0 large bowel cancer). The mean number of bed-days used in the last year by patients who died with heart failure was 20.2, versus 20.5 per patient who died with cancer (range 15.9 lung cancer to 30.4 bladder cancer). Patients with heart failure were admitted on average, 1.5 times in the last year of life, compared with 2.1 admissions for cancer patients (range 1.7 for breast cancer to 3.0 for ovarian cancer). Overall, for patients in this study, bed use in the year prior to death increased with age, from 10 days or less in patients aged under 50 years to 25 or more in patients over 85 years.

Figure 2 Hospital utilisation in the last year of life by cause of death and age, former Oxford region 1996-1998



Comment

Patients with heart failure stayed in hospital for longer periods than patients with cancer, even though they had fewer admissions. As a group, heart failure patients used more acute hospital resources in their last year than patients with any of the five most common cancers. Days spent in hospital by heart failure patients rose with age at death.

The potential limitations of death certification data[144] were discussed in study II. They are considerable, and should be acknowledged. The number of bed days is a statistic that is collected routinely in the UK. However, the completeness and accuracy of NHS bed days is unlikely to be as high as in countries where the health system collects these data for charging patients. In the NHS, bed days provide a general picture of resource use.

Heart failure patients are spending significant periods of time in hospital in their last year of life. Whilst this may represent late recognition of the terminal phase of heart failure by professional carers, it is also possible that there are few alternative care settings. Acute hospitals will not always provide the most appropriate care for these patients. In addition, proximity to death is thought to influence costs more than age, so that finding alternatives to hospital may offer savings to the NHS. This analysis supports the need to question whether heart failure patients are being looked after in the most appropriate terminal care settings.

In the next chapter, I will explore similar issues using a dataset which describes a different population and allows more detailed exploration of the influences on bed usage.

STUDY IV: Use of NHS hospitals in the last year of life- The role of diagnosis and area deprivation. A comparative study of routine data in Scotland.

Introduction

The provision of care at the end of life is an important issue for all health systems. The number of people in their last year of life is rising as western European populations age, and both the demands on services and health care costs are increasing as a consequence.[145] Proximity to death, in particular, is an important influence on health care spending.[146-148]

Experiences at the end of life reflect the impact of current health and welfare policies on longer term advantage or disadvantage. If access to health care has been poor throughout life, patterns of behaviour are set, expectations may be low and morbidity high. Services provided at the end of life therefore have great potential to exacerbate existing inequalities.

Equity in health care is enshrined in the founding principles of the NHS; services should be provided for all, irrespective of issues such as social circumstances or diagnosis. In practice, end of life care is a complex mix of services, and access is inevitably less than perfect. In the USA, extensive variations in end of life care have been documented,[149] even amongst patients in the same regions. To date, little is known about how palliative care may vary in the NHS, though inequities in general care are well documented.

Differential access to end of life care by socio-economic status has been described in small retrospective studies. Cancer patients from socially advantaged areas were shown to have better access to hospice care, and be more likely to die at home than their peers in poor areas.[62;103;105] Analyses of place of cancer death suggest that area level deprivation might have an effect.[150]

Diagnostic inequities in care are also apparent. UK Department of Health guidance recommends that both a palliative care approach and specialist services should be available to all patients.[24] In practice, end of life care rarely extends beyond cancer. General practitioners have also acknowledged the difficulties of providing effective terminal care for people who do not have cancer and called for new services.[3;151]

Despite this, specialists in palliative medicine see few patients with conditions such as heart failure.[152] Non-cancer diagnoses may present common disabling conditions, with poor prognoses[153;154] and a high demand for health care.[155] At the end of life, without the services available to cancer patients, there may be no alternative to hospital for patients with other diseases. Inappropriate use of acute services can offer less than optimal care for the patient, and represent poor value for money for the health service. This study will examine diagnostic and socioeconomic patterns in the use of hospital care in the last year of life. Patterns of hospital use will be compared between patients with heart failure and cancer, assessing the influence of area level deprivation.

Aims

To determine whether or not patients with heart failure have a different pattern of health service use in their last year of life, compared to cancer patients, and whether the patterns of use vary by deprivation of area in which patients lived.

Specific research questions:

Compared with terminal cancer patients, do patients dying of heart failure:

- Have a greater number of hospital admissions and in patient bed days during their last twelve months of life?
- Continue to receive treatment in acute hospitals, until much closer to death ?
- Have a lower chance of dying in the community, rather than in hospital?
- Demonstrate greater inequities in access to care by deprivation of area in which they live?

Materials and methods

This study used the Scottish Record Linkage System. The Information and Statistics Division of the National Health Service in Scotland collects and collates data on all NHS hospital admissions using the Scottish Morbidity Record scheme. This database is linked, using probability matching, to information held by the General Registrar's Office for Scotland on deaths in-hospital and out-of-hospital. This linkage permits analysis of each individual patient's natural history and outcome.

The study population was identified from death records held by the General Register Office for Scotland and the routine hospital in-patient information system, the Scottish morbidity records (SMR1). All patients with a first admission for heart failure (In position 1 of SMR coding form, ICD9 425.4, 425.5, 425.9, 428.0, 428.1 and 428.9) in 1995 and a date of death before the end of 1998. Patients were excluded if they have had a hospital admission for this condition (recorded in any position for the purpose of ICD9 coding) in the 10 years prior to 1995.

These individuals were compared with: Patients with a first admission for cancer in 1995 and a date of death before the end of 1998. Inclusion was restricted to the four most common sites of cancer for men (In position 1 of SMR coding form, lung ICD9 162, large bowel ICD9 153-154, prostate ICD9 185 and bladder ICD9 188) and women (In position 1 of SMR coding form, breast ICD9 174, large bowel, lung and ovary ICD9 183). Patients with any previous admission associated with a malignant neoplasm (ICD9 140 – 208) were excluded from the analysis.

Deprivation category was assigned by postcode sector, using variables from the 1991 census. This is based on the Carstairs composite score, which combines four variables: unemployment (unemployed male residents over 16 as a proportion of all economically active male residents aged over 16); overcrowding (persons in households with one and more persons per room as a proportion of all residents in households); non car ownership (residents in households with no car as a proportion of all residents in households); and low social class (residents in households with an economically active head of household in social class IV or V as a proportion of all residents in households). Z scores are used to standardise the component variables. The Carstairs index is then calculated from the sum of the unweighted Z scores.

Date of death was ascertained from the mortality records for all patients, and data analysed which related to the last 12 months of life. The two patient groups (cancer and heart failure) were compared using the following variables: age, sex, area deprivation category, number and type of admissions to hospital, length of stay, cause and place of death. Time from first admission in the last year of life was calculated to act as an additional measure of access to services.

The dataset was cleaned and episode based data were aggregated to produce a file relating to individual patients using SPSS computer software.[156] Univariate and multivariate analyses were then completed on this dataset, as described below.

Specification of the regression model

Linear regression analysis was conducted using SPSS, with length of stay in hospital as the dependent variable. Scatter plots were made of all variables, singly and in relation to the dependent variables (not shown). Factor analysis was not practical, as the explanatory variables were a mixture of continuous and categorical data. Instead, backwards regression was used, which entered all variables into the first model. As the distributions of length of stay and number of admissions were highly skewed to the lower values, natural log transformations were computed. Initial screening of the models was based on the residual plot, the size of the R^2 and the sign and significance of the coefficients.

The data were examined for outliers and influential variables, by visual inspection, calculation of Studentised deleted residuals and Cook's distances. Standard tests for heteroskedasticity and multicollinearity were performed (Appendix 2).

Data limitations

Data fields relating to operative procedures and type of facility were not used, as they contained many inaccuracies and were incomplete. Similarly, the diagnostic codes beyond principal diagnosis were of limited value. Cases were excluded if the deprivation category was missing (28 cases), recorded age was under 18 years (12 cases) and the length of stay exceeded one year (1 case).

Results

Patterns of health service use by diagnosis

Table 5 lists demographic data for the sample. 4303 patients were admitted during the study period with heart failure as a principal diagnosis, 9602 patients were admitted with cancer. As a group, the heart failure patients were older than those with cancer (median age 79 years versus 70 years), and a higher proportion were females (55.5% versus 46.5%) Distribution within deprivation categories (1 least deprived to 7 most deprived) was similar.

Patients with heart failure were admitted to hospital later in the last year of life than cancer patients (a median of 72 days (mean 120, SE 2.0) from first admission to heart failure death, versus median 109 days (mean 143, SE 1.0) for cancer). A high proportion of admissions for the heart failure patients were emergencies, (59.7% versus 36.9% for cancer patients, $p<0.01$), whereas booked and repeat admissions formed the single biggest category of cancer patient admissions (Tables 7,8). Patients who left hospital to die were discharged at a similar stage, median 23 days for heart failure patients, 24 for cancer patients. For 2029 (50.1%) heart failure patients, repeated admissions in the last year of life were for the same diagnoses. 5853 (61.0%) cancer patients had the same reason for admission on every occasion.

Causes of death are presented in Table 6. Heart failure was the principal cause of death for 1340 (56.4%) of patients admitted with heart failure in the last year of life. 8526 (88.8%) cancer patients had cancer cited as their main cause of death. 3042 heart failure patients (70.7% of heart failure patients in study) died outside of hospital, compared to 8274 (86.2%) cancer patients.

Table 5 Patients first admitted to hospital in Scotland with cancer or heart failure 1995

	Heart failure patients (n=4,303)	**Cancer patients** (n=9,602)	**All patients** (n=13,905)	**Test statistics**
No. males *(%)*	1,913 *(44.5%)*	5,136 *(53.5%)*	7,049 *(50.8%)*	Pearson Chi-Square $X^2 = 96.96$, d.f.=1, p<0.001
Age in years	Median 79, mean 77.6 (SD 9.8)	Median 70, mean 68.9 (SD 11.6)	Median 70, mean 71.6 (SD 11.8, range 22-100)	t test for equality of means t=45.46, p<0.001
Deprivation 1 **(Least deprived)**	182 *(4.2%)*	472 *(4.9%)*	654 *(4.7%)*	Pearson Chi-Square $X^2 = 7.768$, d.f.=6, p=0.256
2	525 *(12.2%)*	1,257 *(13.1%)*	1,782 *(12.8%)*	
3	924 *(21.5%)*	2,011 *(20.9%)*	2,935 *(21.1%)*	
4	1,054 *(24.5%)*	2,379 *(24.8%)*	3,433 *(24.7%)*	
5	713 *(16.6%)*	1,522 *(15.9%)*	2,235 *(16.1%)*	
6	536 *(12.5%)*	1,199 *(12.5%)*	1,735 *(12.5%)*	
7 **(Most deprived)**	369 *(8.6%)*	762 *(7.9%)*	1,131 *(8.1%)*	
Days in hospital in last year	Median 19, mean 32.8 (SD 40.1, range 0-364)	Median 20, mean 28.2 (SD 30.5, range 0-365)	Median 20, mean 29.6 (SD 33.8, range 0-365)	t test for equality of means t=6.33, p<0.001
Number of admissions in last year	Median 2, mean 2.83 (SD 2.51, range 1-31)	Median 3, mean 4.16, (SD 4.48, range 1-67)	Median 3, mean 3.75 (SD 4.02, range 1-67)	t test for equality of means t=-22.39, p<0.001

Table 6 Causes of death in cancer and heart failure patients first admitted to hospital in Scotland 1995

Cancer patients cause of death	No (% of cancer patients)
Lung cancer	4300 (44.8%)
Breast cancer	1721 (17.9%)
Prostate cancer	940 (9.8%)
Ovarian cancer	570 (5.9%)
Bladder cancer	566 (5.9%)
Other cancer	356 (3.7%)
Colorectal cancer	73 (1.0%)
Heart failure	31 (0.3%)
Missing	1045 (10.9%)
Total	**9602 (100%)**

Heart failure patients cause of death*	No (% of heart failure patients)
Heart failure	1340 (31.1%)
Chronic ischaemic heart disease	527 (12.2%)
Diabetes (all related)	213 (5.0%)
All cancer	190 (4.4%)
Pneumonia	156 (3.6%)
Renal failure (acute and chronic)	80 (1.9%)
Chronic respiratory disorders	70 (1.6%)
Other	1376 (32%)
Missing	351 (8.2%)
Total	**4303 (100%)**

*Largest categories shown

Patterns of health service use by deprivation of area

Heart failure patients

Heart failure patients had a higher mean age at death, and showed a trend towards death at a younger age amongst people living in more deprived areas (Figure 3). Compared to all other heart failure patients, those from the poorest areas (deprivation categories 6 and 7) spent a significantly greater number of days in hospital in their last year of life. The mean number of admissions to hospital increased with increasing area deprivation (Figures 4,5). There were no statistically significant differences in time from first admission to death amongst patients in different deprivation categories, though those from the poorest areas had a longer mean time from first admission. The mean time from discharge to death decreased, as area deprivation increased. Patients from the poorest area had a significantly shorter time out of hospital before death (Figures 6,7). There was no pattern to the type of admissions by deprivation category (Table 7). The majority of patients died outside of hospital. Table 9 shows that the proportions of deaths in both settings were similar in each deprivation category.

Cancer patients

Cancer patients from the poorest areas spent fewer days in hospital in the last year, though the differences did not reach statistical significance. There was a definite trend to decreasing numbers of admissions to hospital, with increasing area deprivation. Patients from the poorest areas had a significantly fewer admissions than all other patients (Figures 4,5). Similarly, increasing area deprivation was associated with shorter time from first admission to death. Conversely, the time from final discharge to death was shortest for residents of the poorest areas, but these differences did not reach statistical significance(Figures 6,7). The proportion of admissions classified as emergencies was higher for patients from the poorer areas, whereas the booked and repeat admissions made up a smaller part of the total (Table 8).

(Note that the starting point of the vertical axes in figures 3 to 8 may differ. The number of cases in deprivation categories is given in Table 5.)

Figure 3 Age at death by deprivation category and diagnosis

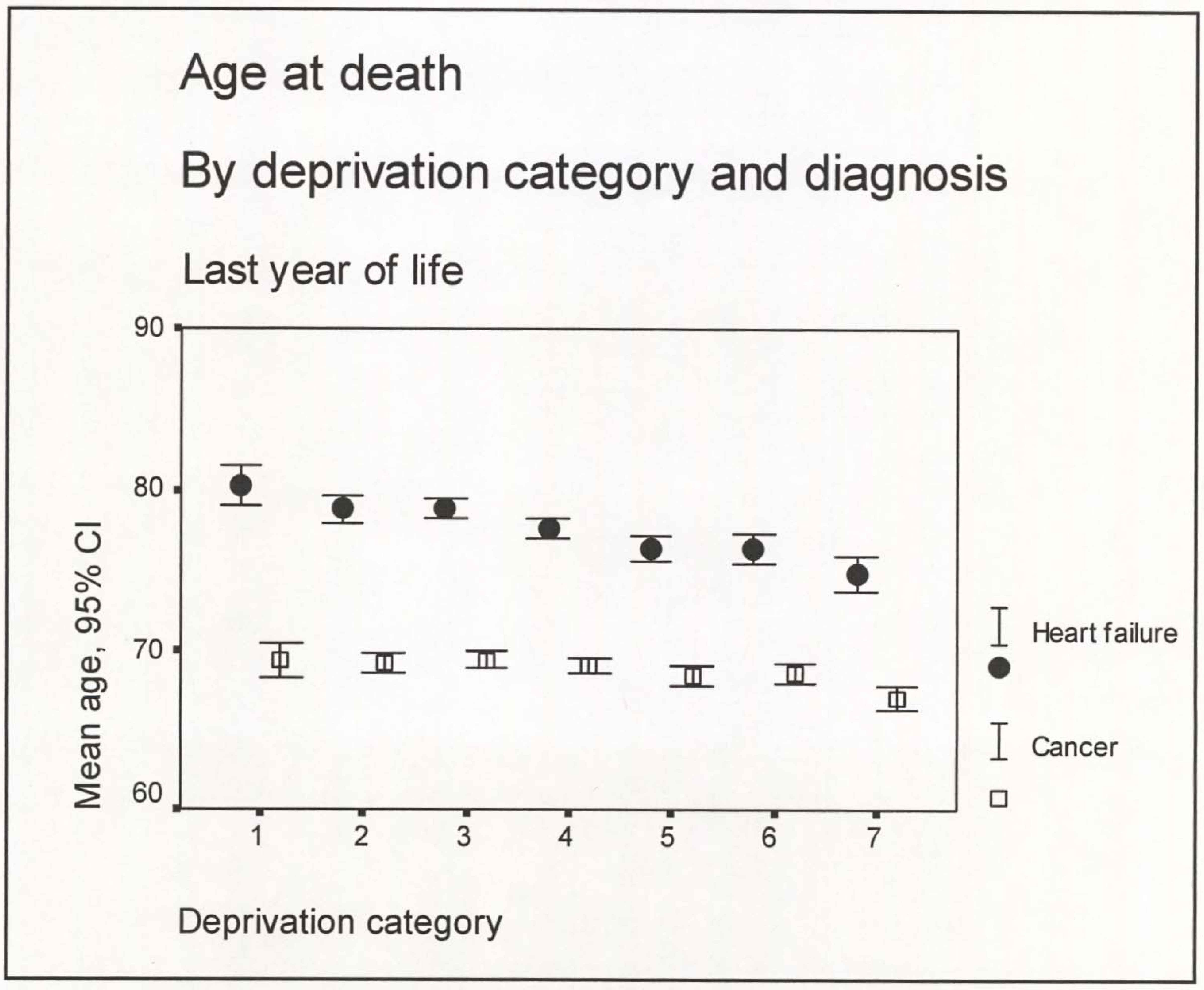


Figure 4 Mean number of admissions by deprivation category and diagnosis

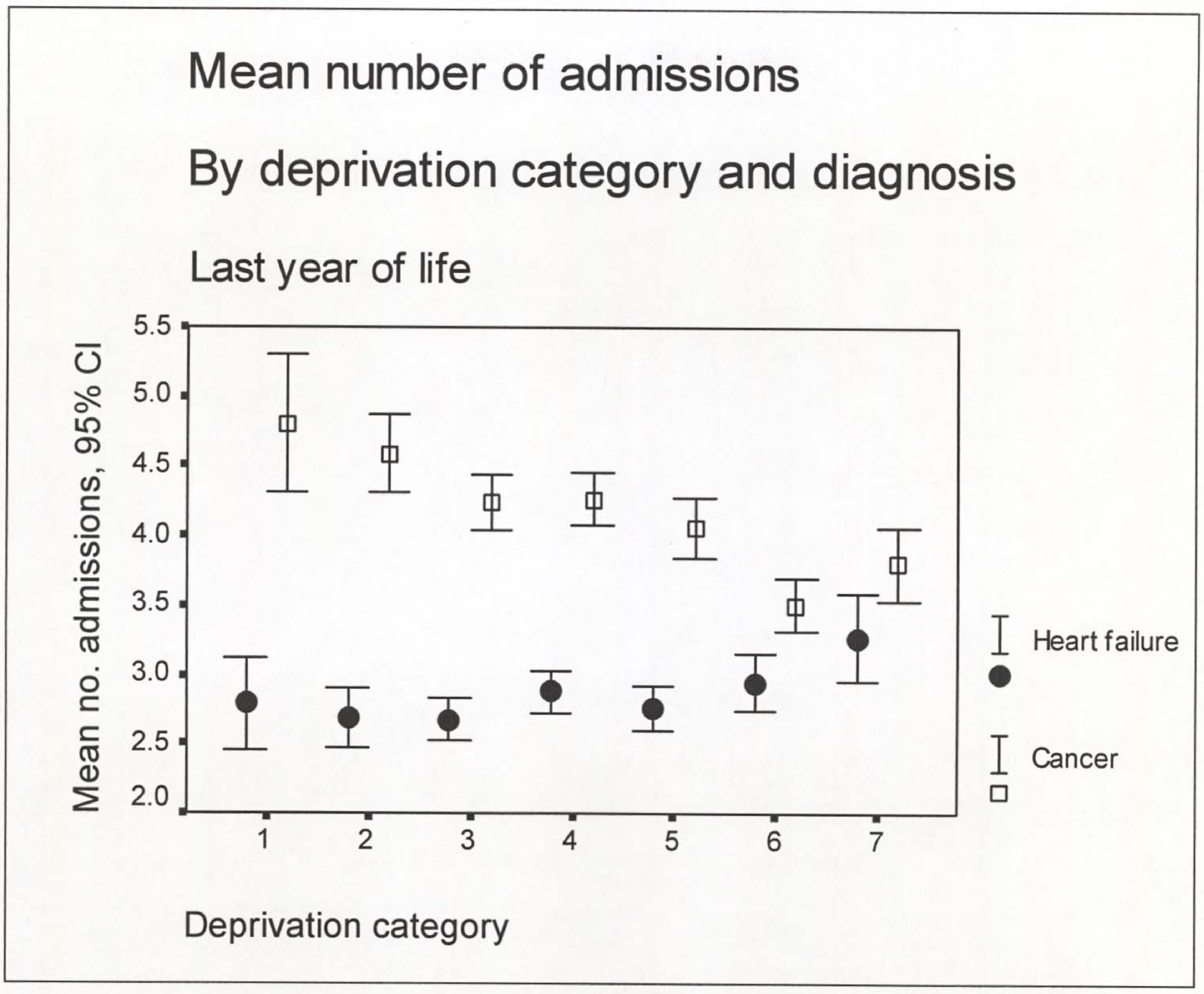


Figure 5 Mean days in hospital by deprivation category and diagnosis

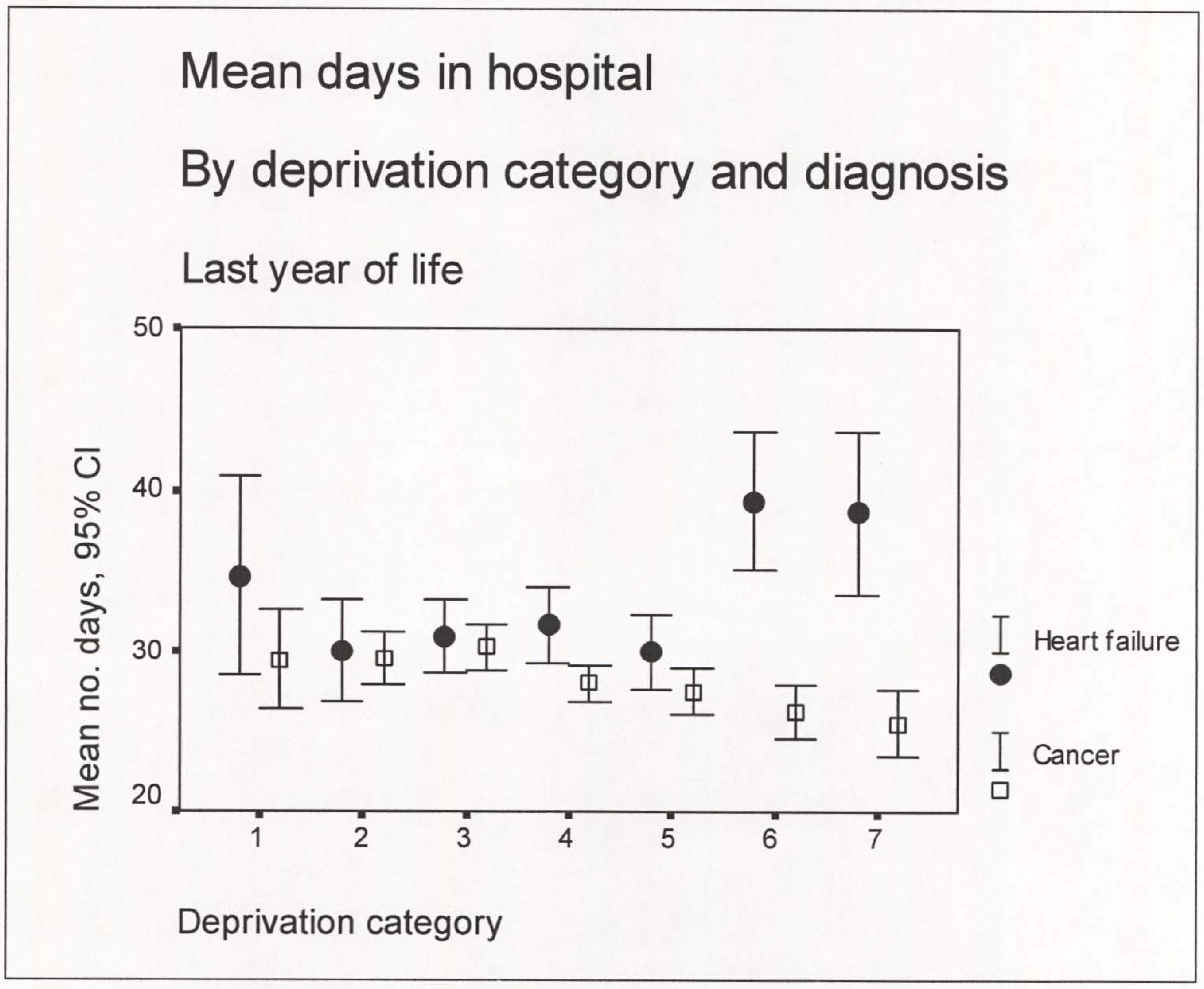


Figure 6 Time from first admission to death by deprivation category and diagnosis

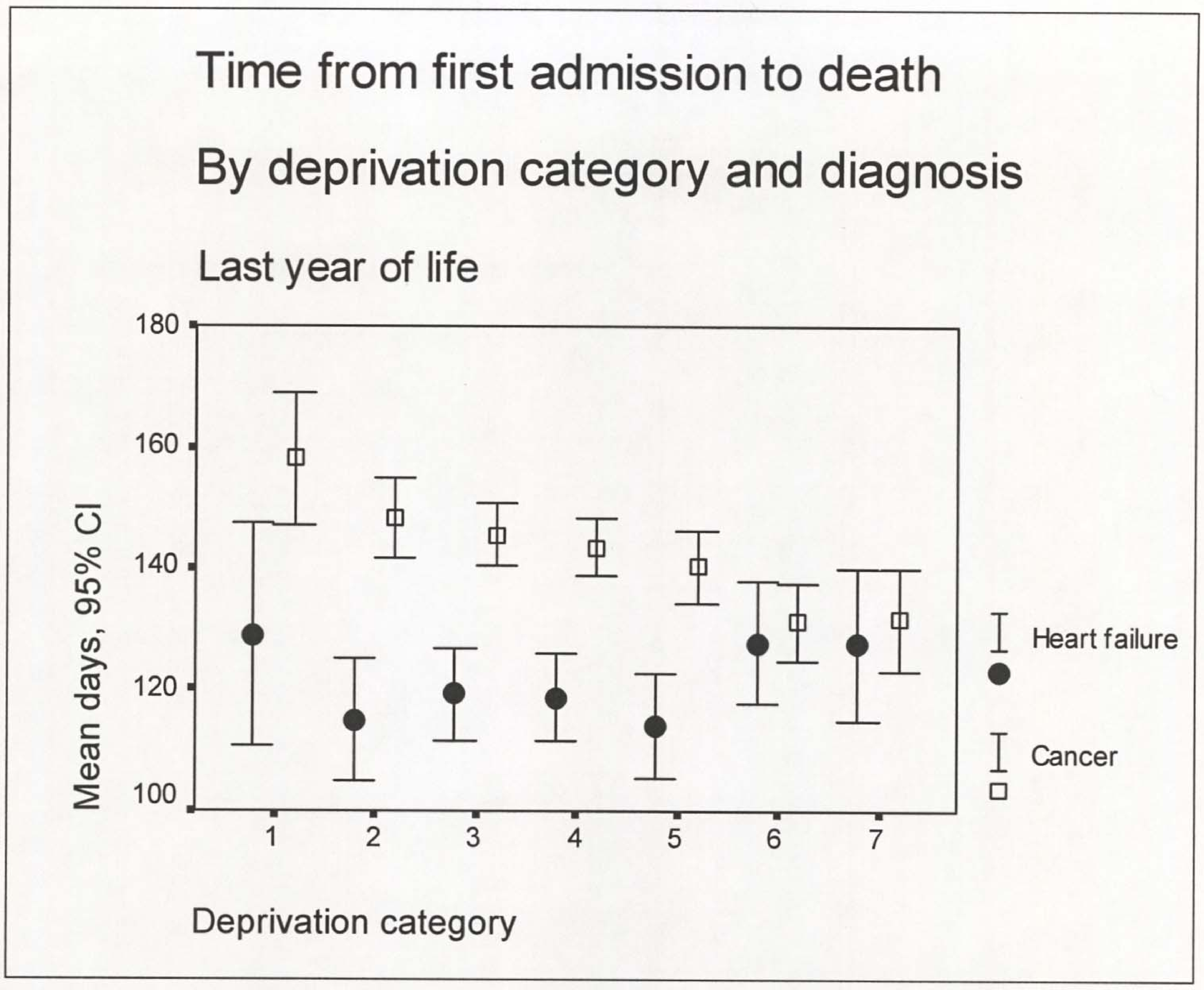


Figure 7 Time from final discharge to death by deprivation category and diagnosis

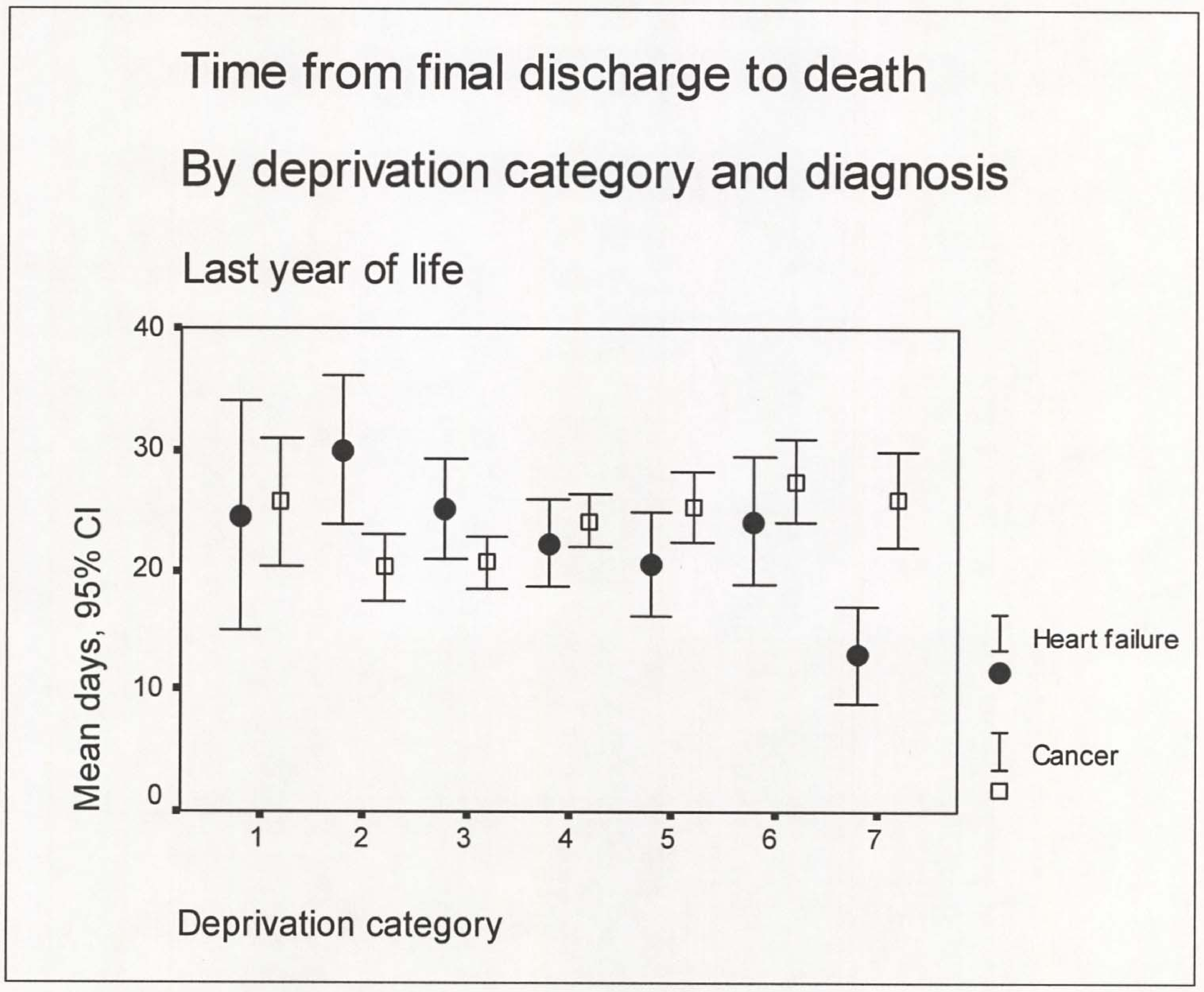


Figure 8 Time from first operation/procedure to death by deprivation category and diagnosis

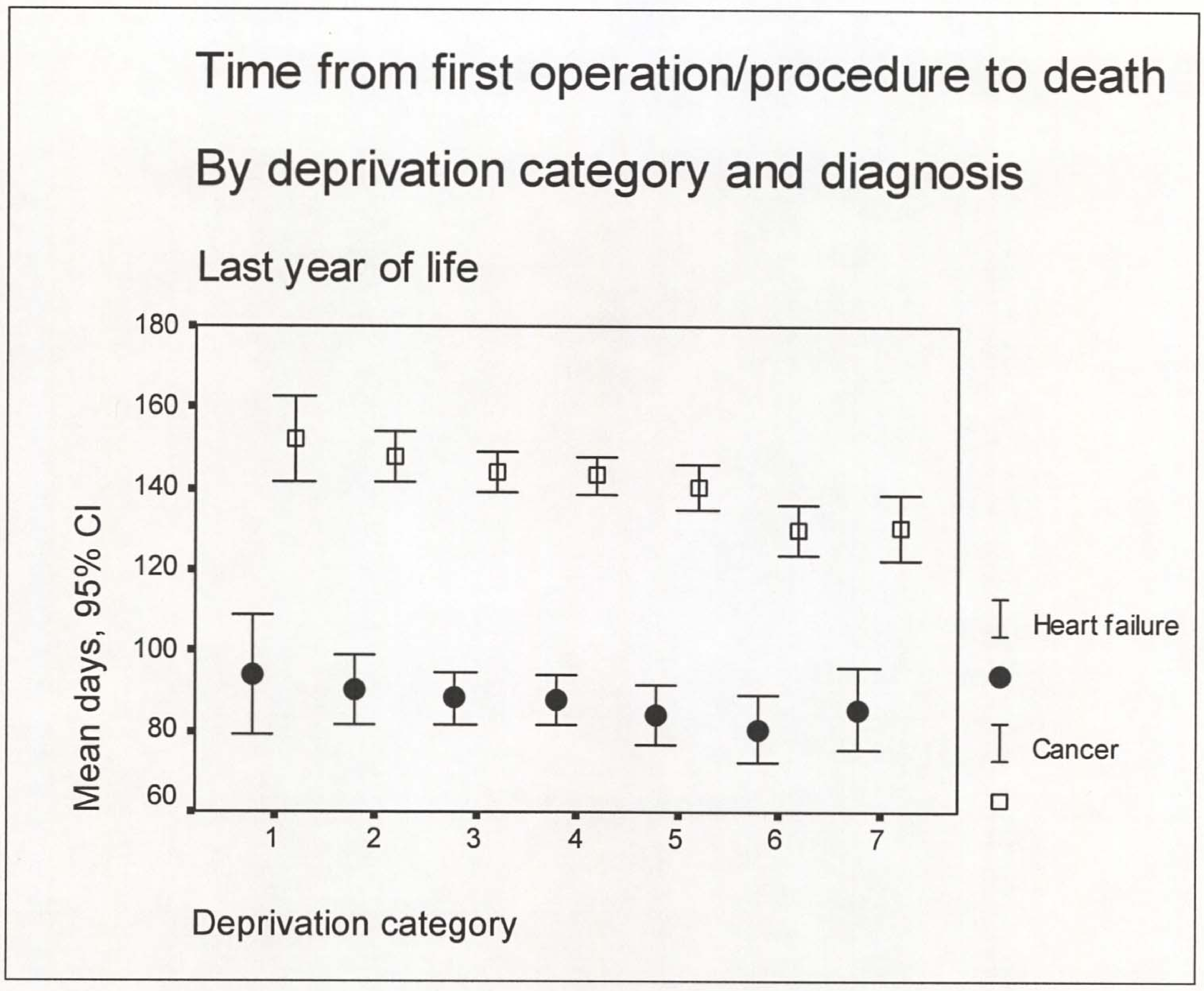


Table 7 Heart failure patient episodes - Type of admission to hospital

Dep cat	Deferred	Booked & repeat	Transfer	Emergency accident & Injury	Emergency other	Totals
1		58 (11.2%)	145 (28.0%)	8 (15.7%)	307 (59.3%)	**518 (100%)**
2	7 (0.5%)	164 (11.6%)	421 (29.9%)	28 (2.0%)	788 (56.0%)	**1408 (100%)**
3	30 (1.2%)	285 (11.5%)	679 (27.5%)	36 (1.5%)	1439 (58.3%)	**2469 (100%)**
4	20 (0.7%)	307 (10.1%)	843 (27.6%)	66 (2.2%)	1817 (59.5%)	**3053 (100%)**
5	22 (1.1%)	188 (0.1%)	589 (30.0%)	27 (0.1%)	1140 (58.0%)	**1966 (100%)**
6	6 (0.4%)	180 (11.6%)	468 (30.1%)	22 (1.4%)	878 (56.5%)	**1554 (100%)**
7	2 (0.2%)	106 (8.8%)	383 (31.8%)	13 (1.1%)	702(58.2%)	**1206 (100%)**
Totals	**87 (0.7%)**	**1288 (10.6%)**	**3528 (29.0%)**	**200 (1.6%)**	**7071 (58.1%)**	**12174 (100%)**

Table 8 Cancer patient episodes – Type of admission to hospital

Dep cat	Deferred	Booked & repeat	Transfer	Emergency accident & injury	Emergency other	Totals
1	18 (0.8%)	1211(53.1%)	275 (12.1%)	7 (0.3%)	771 (33.8%)	**2282 (100%)**
2	16 (0.3%)	2957 (50.5%)	782 (13.4%)	33 (0.6%)	2067 (35.3%)	**5855 (100%)**
3	44 (0.5%)	4281 (50.1%)	1209 (14.1%)	30 (0.4%)	2987 (34.9%)	**8551 (100%)**
4	37 (0.4%)	5076 (50.3%)	1318 (13.1%)	44 (0.4%)	3624 (35.9%)	**10099 (100%)**
5	25 (0.4%)	2874 (46.0%)	925 (14.8%)	27 (0.4%)	2402 (38.4%)	**6253 (100%)**
6	15 (0.4%)	1816 (43.8%)	657 (15.8%)	28(0.7%)	1634 (39.4%)	**4150 (100%)**
7	7 (0.2%)	1284 (44.4%)	487 (16.8%)	15(0.5%)	1099 (38%)	**2892 (100%)**
Total	**162 (0.4%)**	**19499 (48.6%)**	**5653 (14.1%)**	**184 (0.5%)**	**14584 (36.4%)**	**40082 (100%)**

Table 9 Deaths outside of hospital

Dep cat	Cancer deaths out of hospital n (% within dep.cat)	Heart failure deaths out of hospital n (% within dep.cat)
1	412 (87.3%)	127 (69.8%)
2	1096 (87.2%)	369(70.3%)
3	1725 (85.8%)	642 (69.5%)
4	2056 (86.4%)	759 (72.0%)
5	1313 (86.3%)	501 (70.3%)
6	1015 (84.7%)	380 (70.9%)
7	657 (86.2%)	264 (71.5%)
Total	**8274 (86.2%)**	**3042 (70.7%)**

Box 2 Variables included in the first regression model

Data label	**Description**
LNSTAY	Log of total bed days in hospital
AGE_1	Age in years
SEX_1	Sex (male 1, female 2)
DEPCAT_1	Deprivation category (1 least deprived, to 7 most deprived)
cancer	Diagnosis of admission (cancer sites 1, heart failure 0)
Emergency adm(lastbeforedeath)	Type of admission (1 emergency, 0 all other)
Mindysopdth	Time from last procedure or operation to death (days)
Maxdysadmdth	Time from first admission to death (days)
Dieinhospital	Death outside hospital 0, in hospital 1

Model Summary

Backwards regression produced a best fitting model after two iterations. The residual plots and other tests suggested that this model fitted the data well, with no evidence of heteroskedasticity, multicollinearity or influential outliers (Appendix 2). This model (Table 10) was able to explain 20% of the variation in length of stay in hospital (adjusted R^2 0.204). The variables 'depcat' and 'cancer' were excluded. The remaining variables are shown in Table 11. Increasing age, being female, greater time from first admission to death were associated with a longer total in patient stay. More time between final discharge and death, death in hospital and emergency admission were associated with shorter total stays.

Table 10 Regression model summary

R	**R Square**	**Adjusted R Square**	**Std. Error of the Estimate**	**Change Statistics**				
				R Square Change	F Change	df1	df2	Sig. F Change
0.452	0.205	0.204	1.00639	0.205	423	8	13149	0

Table 11 Regression model

	Unstandardised Coefficients		**Stand. Coeffic -ients**	**t**	**Sig.**	**95% CIs for B**		
	B	**SE**	**Beta**			**lower**	**upper**	**VIF**
(Constant)	1.607	0.084		19.183	<0.001	1.443	1.771	
AGE_1	0.014	0.001	0.135	16.065	<0.001	0.012	0.016	1.172
Maxdysadmdth	0.003	0.000	0.330	35.940	<0.001	0.003	0.003	1.395
Mindysopdth	-0.001	0.000	-0.092	-11.389	<0.001	-0.001	-0.001	1.081
Dieinhospital	-0.559	0.027	-0.191	-20.901	<0.001	-0.611	-0.507	1.374
SEX_1	0.072	0.018	0.032	4.046	<0.001	0.037	0.106	1.015
Emergency admission	-0.150	0.018	-0.066	-8.299	<0.001	-0.186	-0.115	1.033

Additional regression analyses

The regression analysis was repeated for cancer patients alone (not shown), including a variable to describe cancer site. This produced a model that was able to explain 25% of the variation in total in-patient stay, suggesting that cancer site was responsible for 5% of the variation in length of stay. Analyses were also performed for cancer and heart failure patients combined, using the number of admissions as the dependent variable. These also explained approximately 20% of the variation in number of admissions.

Interpretation

In this study patients with heart failure were more likely to be older and female than the patients with cancer. Compared to cancer patients, people with heart failure were admitted to hospital later in their last year of life, and a lower proportion of them died outside of hospital. Amongst heart failure patients, residents of the poorest areas died at a younger age, were admitted to hospital more often and stayed for longer. They also spent the shortest time out of hospital before death. The effect of area level deprivation was more marked for cancer patients: residence in the poorest areas was associated with fewer, later admissions, a longer total stay in hospital, and more emergency admissions.

This analysis by socio-economic status has demonstrated the well established trend to death at a younger age amongst poorer people. Cancer patients in higher deprivation categories were admitted to hospital more often than their peers, whilst the trend amongst heart failure patients was reversed. There are many potential explanations for this, but it is plausible that admissions for the heart failure patients can be reduced with effective treatment in the community. Thus, if the people in the poorest areas have worse access to good primary care, they may require more admissions to hospital than heart failure patients as a whole. In contrast, a higher proportion of the admissions for cancer patients are likely to have been for treatments which are not available in the community, such as chemotherapy and radiotherapy. The pattern of care amongst cancer patients then represents easier, earlier access to treatment for residents of more affluent areas.

Time from first admission within the last year, and first procedure or operation were used as measures of prompt access to health care. The overall association between higher socio-economic status and earlier admission amongst cancer patients was reduced when analysed by cancer site (not shown). It may be that the pattern of disease within deprivation categories was responsible for some of these differences.

The regression analysis was able to explain 20% of the variation in length of stay in hospital. Therefore it is likely that there are other influences on hospital stay that were not in this routine dataset. Interpretation of variation in duration of admission is complex, as the duration of the illness episode depends upon both admission and discharge rates. Thus, the number of influential factors is great. Most admissions to hospital are arranged by a patient's general practitioner, and the confidence, competence and usual practice of the individual doctor will influence this decision. The patient's home situation including the availability of support from family, friends or social services is an important factor in decisions to admit to hospital and to discharge home. A long wait for a bed in a nursing home or for social services support may cause a prolonged inpatient stay. Similar arguments apply to the number of times that a person was admitted to hospital in the last year of life, where practical concerns may outweigh clinical considerations.

In this study, the situation is complicated further by the inclusion of two broad diagnostic groups. If my underlying hypothesis is correct, and there are differences in the services provided for heart failure patients versus cancer, then they may face different waiting times for discharge arrangements to be put in place. For example, if night time nursing is needed, Marie Curie service is available to cancer patients, but not usually to those with heart failure. Thus, a longer duration of admission for patients with heart failure may indicate fewer community resources available, rather than a greater need for in-patient care.

Data from Scotland were used because it is the only large area in the UK where mortality and hospital statistics are linked. However, much of Scotland is sparsely populated and a high proportion of the population resides in the central belt between Glasgow, Edinburgh and Dundee. Travel time to hospital will be great for residents of the islands, and much of the mainland. Distance from home is likely to lower the threshold to admit to hospital, and conversely, to prolong admission. If patients were being seen in tertiary centres, this may mean that travelling distances were substantial, even within more populous areas.

The quality of the routine data may limit the robustness of the findings. However, completeness approaches 100%, and data accuracy is good, with ascertainment exceeding 90% for heart failure and 95% for the common cancers.[157] The exclusion of variables with many missing values was a conservative approach, but allows the findings to be presented with some confidence. Bed use was the main measure of resource use, as procedure fields were incomplete. Although this meant that theories relating to reasons for admission could not be tested, bed days account for over 90% of NHS costs.[158]

The study sample was selected by year of first admission to hospital, and confined to patients who went on to die within four years. All patients had gained access to secondary health care at a similar point in their life journey, and those who had lived with a diagnosis for many years were excluded. It was expected that this would include a majority of heart failure patients, and exclude people with cancers with which people may live for many years.[159] This method facilitates comparisons between diagnostic groups, as all were similarly near to the end of their lives. It also strengthens comparison by area deprivation, by excluding those with long illness durations who may otherwise have obscured any social differences in access. Four years was considered to be a sufficiently long period to ameliorate any initial inequities in access. Proximity to death is one of the greatest influences on health care costs,[160] so that this study is a good design from which to draw conclusions on costs.

In the multivariate analysis, it appeared that deprivation category had little influence on either total length of stay in hospital, or the number of admissions (not presented). It is a limitation of the study that an individual measure of socio-economic status was not available. Area level deprivation provides a convenient proxy, but is liable to the ecological fallacy, as not everyone within a poor area will be poor. The populous urban areas in Scotland may pose a particular problem in this respect.

Implications

Patients with heart failure are a large and vulnerable group who are recipients of end of life care in the NHS. It is important that their needs should be acknowledged by health services. This study could not look at the content of the care received, but it does raise the question of whether other settings would be more appropriate for some patients. It is likely that a number of admissions to hospital could be avoided with improved community management of heart failure. This should be a priority for the sake of both patient and health system.

In an equitable NHS, patterns of care by area deprivation are unacceptable. This study suggests that for cancer patients, in particular, where they lived did affect their access to health services. Confirmation of these findings is needed with individual measures of deprivation, separating cancers at different sites.

Given the differences in service usage between heart failure and cancer patients, the role of the health professionals involved should be examined. In the next chapter, I study the most influential group – doctors. Using qualitative methods, I explore doctors' perceptions of the need for palliative care beyond cancer.

Study V (a): Doctors perceptions of palliative care for heart failure. A focus group study with consultants and general practitioners in the north west of England

Study V(b): Doctors' understanding of palliative care

The next two chapters are drawn from one piece of qualitative research. The first presents an overview of a series of focus groups with doctors that explored doctors' perceptions of the need for, and barriers to, palliative care for heart failure patients. The second paper is an analysis of doctors understanding of palliative care derived from the same focus group discussions. This is central to any consideration of service development.

Study V (a): Doctors perceptions of palliative care for heart failure A focus group study with consultants and general practitioners in the north west of England

Introduction

Heart failure is a common condition. At the beginning of this thesis I reviewed estimates of prevalence, which range from 2 to 10 per 1000 population.[161] The incidence is rising as more people survive acute coronary events. The median survival for heart failure (16 months after first hospital admission) is worse than many of the common cancers.[154] Despite this poor outlook, those who die with the condition in the UK seldom access specialist palliative care services, and responsibility for their care lies with primary care, cardiology, geriatrics or general medicine. Palliative medicine grew out of the hospice movement, and cancer charities still make a substantial contribution to the costs of palliative care. This, coupled with professional doubts over the wisdom of expansion,[162] means that specialist care of the dying is virtually synonymous with cancer care in the UK.

However, in recent years there have been calls to recognise the palliative care needs of people with heart failure.[152;163;164] The National Service Framework for coronary heart disease endorsed this view, but failed to address the question of how it should be provided, or to identify new sources of funding.[14] As the research evidence for unmet care needs in terminal heart failure grows, it has not been accompanied by investigation into appropriate models of care. Patients dying with heart failure may have unpredictable illness trajectories; understanding and expectations will also be different from patients with terminal cancer. Health professionals' needs for support and experience with palliative care for heart failure are also likely to vary. Box 3 suggests aspects of palliative care that may not be readily available to people with heart failure.

Box 3 Aspects of palliative care that may not be available to patients with heart failure

Services

- Multidisciplinary support in the community[14;164]
- Specialist nurse practitioners[165;166]
- Access to in-patient palliative care beds
- Professional carers trained in the principles of palliative care[164]
- Social and financial support comparable to that of cancer patients.

Approaches

- A strategy for a timely move from invasive treatment to supportive care[164]
- Optimisation of treatment of the underlying disease[152]
- Improved symptom control[152] and attention to co-morbidities
- Emphasis on quality of life[152]
- Discussion of prognosis[20] early in the disease course, seeking patient views[164]
- Acknowledgment of disease specific barriers to effective communication[20]
- Better information for patients[166]

In the absence of an evidence base, doctors' views on terminal care for heart failure patients are likely to be influential in shaping the development of future care. In this study, focus groups were used to explore doctors' views of palliative care for people with heart failure, and identify barriers to improving the care of this group.

Participants and methods

The paucity of previous research meant that this study was exploratory; hence focus groups provided an appropriate approach. Apart from being an efficient means of data collection, they allowed the participants to use their own frames of reference and identify the topics that were important to them. Clarification of views through discussion and debate was particularly valuable for a topic to which the participants may not have given much prior consideration.

Sampling

Seven single speciality groups of doctors were recruited; two each of general practitioners and consultant cardiologists, and one each of consultants in geriatrics, general medicine and palliative medicine. These were chosen to reflect the specialities that are most involved with patients with heart failure. Participating doctors were recruited from tertiary referral centres (one cardiologist group), teaching hospitals and district general hospitals to ensure access to a wide range of views. One general practitioner group was made up of doctors with either a teaching or research post at a university. A pragmatic approach to recruitment was taken, and participants were found from a number of different sources, depending on circumstances.

Table 12 Recruitment and Participants

Group	Number in group (No. males)	Method of recruitment
General Practitioners	5 (4M)	Written invitation to practices in one area, allied to a research consortium
General Practitioners (teaching and academic)	5 (5M)	Written invitation to doctors employed by one university
Cardiologists from district general hospitals	5 (4M)	Written invitation and telephone calls to cardiologists in hospitals in one region
Cardiologists from a tertiary referral centre	3 (3M)	Introduction by member of study steering group, written and telephone invitations
Geriatricians	6 (5M)	Introduction by secretary of the British Geriatric Society, written invitation plus telephone calls
General Physicians	4 (2M)	Written and telephone invitations to physicians at hospitals in one area
Palliative Care Physicians	6 (1M)	Introduction via member of steering group, held after sub-regional meeting

All the hospital and palliative care doctors were National Health Service consultants

Data collection and analysis

The focus groups lasted an average of 80 minutes. A topic schedule was developed to address the study aims, using published literature and previous experiences. The groups were also encouraged to raise their own issues. The same facilitator and observer attended all the meetings, which were tape recorded and transcribed.

These two researchers then coded all the transcripts using Nvivo software.[167] The data were analysed using the principles of constant comparison.[168] The tapes were scrutinised before examining the transcripts, and for checking of final interpretation. Emerging themes and categories were identified independently, and agreement reached by discussion. The two researchers were from different disciplines, and only one had prior knowledge of the area of research. The reliability of the findings was enhanced further by scrutiny from the steering group that included practising clinicians.

Results

Organisational barriers

The workings of the system were a concern for many of the hospital doctors. Care for patients dying with heart failure was described as un-co-ordinated, with patients bouncing from hospital to community and back again. Repeated admissions to different consultant teams were common, and patients' medical notes were sometimes said to arrive on the wards after the patient had been discharged or died. A picture was painted of poor quality care for the patients and frustration for the doctors involved. The lack of continuity in current medical practice was highlighted by the geriatricians and palliative care doctors. All the groups felt that poor community support contributed to repeated hospital admissions.

.'And there are no proper links between our management structures and the community management structures, and this lack of seamlessness in the management of these patients needs to be dealt with…The trouble is because the consultants are managing patients in isolation when they're on the wards and the general practitioners are trying to manage them at home, they're falling between two stools, and that seems to me to be a real problem.'

(Tertiary centre cardiologist 2)

'..I think its something that's been lost in modern medicine, the continuity of care and not just in heart failure, across the board. I mean I'm ashamed of the way we treat patients in our hospital. You can be discharged on a Monday; you can be re-admitted on Wednesday…' (Geriatrician 5)

Adequate basic services, such as district nurses and social services, were considered to be a higher priority than more sophisticated forms of palliative care. Whilst hospital colleagues empathised with the general practitioner struggling to cope without support, the palliative care doctors and cardiologists were also concerned about the impact of the quality of care provided by the general practitioner.

Implicit in the discussions was the impression that care for people dying with heart failure had not been planned. This was most clearly expressed by the cardiologists, who acknowledged the need to develop those formal and informal connections between specialities that are essential to coherent care. All the groups suggested that different models of care in the community might be needed. The concept of a 'key worker' was raised as a possible solution by both general practitioners and cardiologists. This is a model seen in psychiatry whereby a member of the team co-ordinates and oversees the care received.

Prognostication

Unlike cancer, the diagnosis of heart failure does not begin with bad news, and when to initiate palliative care is a difficult question that was discussed by all the groups. The path of chronic heart failure is unpredictable, with half of patients dying suddenly. Stories were told of patients being admitted near to death and being pulled back from the brink. Other patients were perceived as being 'quite well', but able to switch from this state to 'terminal' very rapidly.

The uncertain prognosis of heart failure meant that doctors were concerned about the impact on the patients of giving bad news too soon. This was termed the 'therapeutic and anti-therapeutic' use of prognostication by one general practitioner, and generated different concerns in the speciality groups. For the cardiologists, their major fear was of saying the 'wrong thing', and the patients 'losing faith' in their professional carers, whereas the general physicians did not want to see the patients give up the fight for life. The wider implications for the family and carers were raised by the general practitioners.

'But even when you're at the very end and it's the last few weeks, you still don't know whether they're going to just die suddenly now or whether over the next few weeks they're just going to gradually drift away. So that does make it more difficult in trying to prepare them and their relatives for what's actually going to happen.'

(Cardiologist 3)

Increasing openness about prognosis brought with it growing demands on doctors, and patients were felt to need a lot of psychological support. The doctors portrayed themselves as bad prognosticators, admitting that they may accept the poor outlook late in the illness. Patients, carers and nurses were all suggested as more realistic predictors. As the beneficial effects of open communication in terminal care were acknowledged, this may have represented an unwillingness to engage with difficult issues.

'..It's very difficult, you can't really say who's going to recover .. you know sometimes they respond and sometimes they don't. So its this sort of roller coaster type of thing and its very difficult to give a prognosis other than 'well its his heart, it is serious you know.'

(General Practitioner 1/3)

Doctors' roles

Although many participants agreed that the general practitioner is a central figure in palliative care for heart failure, there was some questioning of the appropriateness of the involvement of specific groups. The most severe criticism was reserved for the cardiologists, who were charged by all groups with failing to recognise palliative care needs or practice holistically. In contrast to their colleagues' image of them, cardiologists articulated an approach supporting teamwork, common goals and a willingness to involve whoever has the appropriate skills. They also appeared to place most importance on dialogue between the specialities to improve care in the future.

'I think one needs to meet with the two specialities [cardiology and palliative medicine] to work the thought and processes through a bit. ... there's too much of a gap between .. the way I practice and what I vaguely perceive is available on the

other side. And I'm trying to reach out every so often for specific patients to be supported, and partly its my lack of knowledge and uncertainties as to what to call for, that's holding things back.'

(Cardiologist 2)

The palliative care physicians were generally viewed favourably by their colleagues, though the need for their speciality was questioned by some general practitioners, who felt able to manage their own dying patients. For these general practitioners, the palliative care specialists were inaccessible, or liable to 'steal' the general practitioners' patients.

The general practitioners saw themselves at the centre of things, both providing and co-ordinating care. This was echoed by the geriatricians, who argued for care provided by community services, supported by others. The perceived inability of palliative care doctors to manage heart failure competently and the unwillingness of cardiologists to provide palliative care were used to justify this approach.

'I mean I haven't come across a palliative care physician yet who's comfortable in treating heart failure. So I'd have said that that it should be the physician who's interested, the general practitioner, the district nurse…if they're heart failure nurses, well great.. I really think [specialists in palliative medicine] should, instead of further fragmenting the service, go back to supporting the primary care team, the general practitioner and the district nurse.'

(Geriatrician 1)

The future

The participants invested some hope in the National Service Framework as a means of increasing funding in palliative care for heart failure. A need for discussion and links between specialities was acknowledged chiefly by the cardiologists. In contrast, all the groups talked at some length of an enhanced role for nurses. The nurse was seen as a figure who could follow patients into the community after hospital discharge, liaise between primary and secondary care, ensure that treatments were adhered to and mobilise appropriate support.

'...Specialist nurses that ... will keep a focus on the whole picture. And where that individual then goes or whether they're admitted or not, [the nurses] can then pick it up and co-ordinate the service so that the total global picture is kept in focus. So that should be ... relatively easier to notice a trend and then intervene with a palliative care approach at a more appropriate stage.'

(Geriatrician 4)

'..I see her [the heart failure nurse] facilitating or passing on her expertise to the primary care team and saying .. this is the programme I want to follow for the next few days, if its not working give me a bell ...'

(Geriatrician 5)

Interpretation

Doctors in the study did not dispute the place of palliative care for patients dying with heart failure. However, this study identified important potential barriers to the development of a palliative care approach to this patient group. These barriers arose from three main areas: the organisation and delivery of services, the course of heart failure and doctors' views of their colleagues' roles.

Strengths and limitations

From the outset, this study was intended as a forerunner to research with nurses, patients and other groups across the UK. Doctors were chosen as a starting point because of their role in shaping demand for services. However, it should be acknowledged that a study involving one professional group cannot expect to generate anything other than cautious conclusions about a multidisciplinary subject such as palliative care.

This study was novel, and made appropriate use of focus group methodology to generate issues for further investigation. The pragmatic approach to recruitment is justified by the pressures on clinicians' time, and low response rates to research studies. However, as participants in the study gave their time voluntarily, it is likely that they were more motivated and interested than average. Use of single speciality groups aimed to minimise the impact of power relations between the interviewees, and limit the disparity between their public and private accounts. The data were analysed by a medically qualified doctor and an experienced qualitative researcher. The high level of agreement between the themes generated independently by researchers with different perspectives increases the confidence in the results.

The findings point to the need for health professionals to give greater thought to the care of patients dying with heart failure, clarifying the roles of doctors and nurses in different specialities and possibly reshaping the services provided. Clearly, these are the priorities of doctors, and they may not reflect accurately the patients' experiences. Investigations into the concerns of dying patients with non-cancer diagnoses have tended to focus on the impact of the disease on the individual, rather than organisational issues.[20;169;170] However, heart failure patients have been shown to have worse access than cancer patients to a range of community services, even when attending a dedicated clinic. These patients also identified a need for their professional carers to improve their dialogue with each other.[169] Prognostication in heart failure is particularly uncertain, but other problems are shared by patients with chronic progressive conditions. Studies of patients with chronic obstructive pulmonary disease have highlighted similar lack of continuity in care and the need for a more holistic approach.[171;172] Communication with doctors is a common source of dissatisfaction for palliative care patients of all diagnoses.[20;173;174]

Implications

The participants gave graphic descriptions of the current inability of the National Health Service to deliver what they saw as an acceptable level of care to this patient group. Many of the issues they raised were not specific to the care of heart failure, or even to end-of-life care. Correcting such 'system failure' and challenging attitudes that inhibit collaboration are long-term goals. In the short term, it is likely that practical solutions for some of the component problems would improve the lot of the patient dying with heart failure. For example, greater use of information technology could ameliorate some of the organisational deficiencies described, for example. The majority of doctors in the study were enthusiastic about developing the role of the nurse in terminal heart failure. They described an often superior ability of the nurse to liaise with other specialities and communicate with the patients. Underlying this is a dilemma often seen in general practice, that of balancing a desire to maintain ownership of an area of care, with existing heavy workloads. The solution proposed goes some way towards avoiding the competing claims to holism amongst medical specialities. A nurse with expertise in cardiac palliative care is ideally placed to act as a co-ordinator of services, as well as influencing medical practice. However, delegation, rather than empowerment, does not remove the question of which speciality should take the lead. In recent years, a number of nurses have been appointed to work with heart failure patients, usually attached to a hospital cardiology centre. Research suggests that specialist nurses may reduce the number of hospital re-admissions and improve disease management for patients with heart failure discharged back to the community.[165;175] A role in palliative and terminal care has yet to be defined, though specialist palliative care nurses such as the Macmillan service provide a successful model that could be adapted.

As the palliative care needs of patients with heart failure are acknowledged, the demands on health and social care services in the community are likely to increase. Furthermore, there is growing recognition that palliative care services need to be integrated into primary care.[176] Recent changes in the NHS, such as the introduction of joint commissioning by health and social services, and the development of primary care trusts, may, in the long term, herald a more favourable attitude to developing community support for patients with heart failure. Whilst primary care trusts are in their infancy it may prove difficult for them to innovate and develop services. Although primary care trusts are to control approximately three-quarters of the National Health Service budget, they are immature organisations, with unproven processes and inexperienced personnel.[177] It also seems unlikely that palliative care for heart failure will be a high priority compared with many other targets that are explicitly highlighted in National Service Frameworks. However, with the prevalence of heart failure increasing, planning for the needs of people dying with heart failure in the National Health Service must become a priority issue.

Conclusions

- Barriers to adopting a palliative care approach in heart failure care relate to the current organisation of health services, the difficulties of prognostication and doctors' understanding of roles and responsibilities.
- Doctors feel that the general practitioner should be the central figure in palliative care for heart failure, supported by specialist colleagues.
- Doctors' future priorities are developing the role of the nurse, increasing essential community services, such as district nursing, and improving communication with colleagues.

In the next chapter, I will explore the more general issue of what doctors' understand by 'palliative care'. This is an important step on the path to ensuring that the same services are available for all.

STUDY V(b): Doctors' understanding of palliative care

Palliative care has been challenged to share its message with a wider audience, and for many years it has been articulating an approach that is suitable for all patients. However, it is not clear how widely this message has been accepted. As part of a study into end-of-life care for heart failure, seven focus groups were conducted with doctors in general practice, palliative medicine, cardiology, geriatrics and general medicine. In these, doctors' understanding of palliative care was explored.

Introduction

Palliative care was challenged to share its message with a wider audience,[178] and through education and example, its proponents have been working to improve care for the majority for nearly 40 years. However, despite the rapid growth of specialist palliative services and ideas, it is widely held that care of the dying is poor, particularly in hospitals.[141;179;180] The approach espoused by the hospice movement is potentially relevant to every area of medicine,[16] and the key to improving health care of the dying must lie in mainstream services. Specialist palliative care services see only a small minority of dying patients, most of whom have cancer.[101] In other diagnostic groups, such as respiratory and cardiac disease, patients' needs for care and support often go unmet.[20;181] As the debate over widening the responsibilities of the specialist services goes on, it is timely to stop and consider what doctors in general understand by palliative care.

Previous investigations into doctors' perceptions of palliative care have often focussed on exploring choice of topics for educational interventions or testing knowledge.[182;183] We know much less about how palliative care is interpreted or conceptualised.[184] This is important, as acquiring knowledge is only one step towards changing practice. The influence of different factors on the complex path between education and behavioural change is increasingly recognised as important.[185;186] Awareness of doctors' beliefs, for example, is thought to be crucial.[187]

The hospital setting is a particularly important setting; almost half of the UK population die there,[188] and popular belief holds that hospital practitioners may be more reluctant than their community colleagues to adopt holistic approaches to care.

This analysis provides essential baseline information for the future development of services and a palliative care approach, by reporting on doctors' understanding of palliative care, as expressed during the focus group discussions.

Findings

Discussion was lively in all the groups except the meeting of general physicians. The specific findings are presented in terms of the main themes arising from the discussion. This is not meant to imply that all the doctors shared one view. Development and refining of ideas was apparent throughout the interviews.

Much more than a service

It was clear from the way that participants referred to palliative care that it was conceived as much more than a service. Terms such as 'mode', 'concept' and 'situation' were used when discussing palliative care. Some framed their talk in aspirational terms, referring to their ideal as 'proper palliative care', or 'a thorough palliative care approach.' The appropriateness of palliative care was not questioned, and even when the group did not share definitions, they were united in their support of palliative care as an ideal. There was also a strong sense of the holistic aspects of palliative care throughout the groups.

'I think in a perfect world you see it as a holistic ideal, encompassing the patient, their family and the problems the patient has, the problems the family has erm and both of their expectations of the process that they're going through. That would be an ideal world.'

(General practitioner 1/3)

The importance of looking at the whole picture including psychosocial issues was expressed in most groups. GPs and cardiologists also discussed the spiritual aspects of care, though there was no particular indication that they felt it was relevant to their work. Communication with patients and cares was also acknowledged as a major aspect of palliative care.

'I think.. it's a kind of cultural recognition of whats death. And, like you were talking about, there didn't used to be palliative specialists, I think there were often

priests that would help.'

(General practitioner 1/2)

'Erm I think palliative care depends on patients and their carers, certainly in cancer but also in heart failure, understanding the condition, the terminal nature of their condition, and what we're trying to do for them.'

(Cardiologist 4)

Palliative care was also portrayed as a phase in time, when the goals of medical management change and death is recognised. It was only through discussion in the groups that the difficulties of recognising the right time to switch to palliative care surfaced as a major challenge.

'A change of gear, a diagnosis of dying, switching from erm officiously striving to keep someone alive er, to where the main emphasis should be on comfort ..'

(Geriatrician 3)

Managing Dying

The management of dying was an underlying theme to much of the discussion. Participants drew a picture of themselves as conductors of the services around their patients, coordinating and facilitating. For some, this encompassed the environment and the social context as well as the medical care. The geriatricians' discussion suggested that they felt that they should strive to manage the death, whilst the cardiologists were honest in acknowledging that they made this switch late in the illness.

'I think what you're trying to do with palliative care is ..... provide the sort of psychological, social support to relatives and patients and to hopefully have a co-ordinated approach so it doesn't collapse at the weekends,- things like that.'

(General practitioner 1/1)

'It's a co-existent approach, so you keep optimising, keep revising the treatment and balancing the combination. But then you are also aware of the other factors that are coming in and you also then get a picture in your mind that is a road to

deterioration. And yes we might stop hammering the ACE inhibitors because they're clearly not effective and we may be bringing them something else for the symptoms, but you're still maintaining that approach.'

(Geriatrician 4)

Not very medical

The role of the nurse was emphasised strongly by most groups, and there was a parallel perception that palliative care was not necessarily the province of the doctor. It was 'not very medical', and 'largely nursing based care for people who are terminal'. There seemed to be a complex set of conflicting motives here. Firstly, it was apparent that palliative care was perceived as being time consuming, and time was openly prized by many of the doctors. Secondly, palliative care was seen as straightforward medical practice, and in the words of one of the consultants in palliative medicine, was 'not glamorous'. If the status of doctors is enhanced by displays of expertise and technical knowledge, palliative care offers a burden with no return. Labelling palliative care as the role of the nurse perhaps legitimises the doctor's choice not to become involved. However, the concept of palliative care as an ideal was pervasive in the groups, and some participants were clearly ambivalent about the role they played. The presentation of the nurse as having the skills and the time to provide better care for the dying may well have been an direct and pragmatic response to the time constraints of their own jobs.

Quantity versus quality

Many of the treatments for heart failure address both symptoms and survival, so the switch from rescue to comfort may not be clear cut. Some of the participants appeared to confuse the introduction of palliative care with a direct path to death and a focus entirely on quality of life. Palliative care was described by one geriatrician as 'quite negatively focussed in terms of survival.' The idea that different approaches may co-exist, with shades of grey in patient management, had not been universally adopted.

The role of the specialist

Neither the GPs nor the hospital doctors expressed clear ideas of how palliative medicine should contribute to heart failure care. A number had unsuccessfully tried to refer patients to their local specialist service, and were disparaging about the narrow remit of the specialist palliative care service. However, the strongest emotion was expressed by some of the GPs and geriatricians who were keen not to hand over their patients to another specialty.

'After all you know the mortality of life is 100%, everybody is dying, so what is the difference between palliative care and good medical practice? You know there are textbooks of palliative care and there are palliative care 'specialists', why palliative care, why not just an ordinary doctor? Its sort of a speciality driven by prognosis rather than anything else, because there are lots of chronic disease that we look after that we cant cure they don't come under the umbrella of palliative care – diabetes for example.'

(General practitioner 1/3)

A few individuals described examples of successfully employing advice from their local consultants, but others felt that palliative care physicians may not have the expertise that they had to deal with heart failure. The palliative care doctors' vision of themselves as educating health professionals to provide most of the support had, on the whole, not been embraced by the other doctors.

Permission to fail

The cardiologists were frank in admitting their dislike of failure, which was how they perceived the death of a patient. In other groups, failure was not always articulated, but it was apparent as they described struggling to find the right words for relatives, the limited time they had for dying patients on ward rounds and the difficulty of accurate prognostication. The palliative care physicians were widely admired for having the ability to 'fail well'. The introduction of the specialty appeared to be a relief for some doctors, and permission to let go. However, a number of doctors in different specialities were concerned at the message this sent to the patients, and one described the attention from specialists as 'ghoulish'.

Interpretation

The study participants displayed an understanding of the wider concept of palliative care, but relatively poor grasp of the role of the specialist in palliative medicine, and scepticism about their role beyond cancer. There was also a strong perception that palliative care is the province of nurses rather than doctors.

Limitations

The themes described here offer a unique insight into doctors' understanding of palliative care, and raise issues for further research. However, it should be acknowledged that the participants' views may not be typical. With the exception of the general practitioners who received locum payments, they were not rewarded for their involvement. The extent to which the views offered provide an accurate picture of physicians' practice is unknown, and the use of standard definitions by some participants to describe palliative care may reflect a willingness to conform to accepted norms. By combining responses to a direct question with implied and direct references throughout the discussions, this potential limitation should be overcome. At times, the term 'palliative care' was used by interviewees to refer to specialist services and elsewhere to a palliative care approach. Which of these meanings was being used was usually clear from the context of the discussion. In general, the flow of discussion was not interrupted by stopping repeatedly for clarification.

Implications

The study participants were familiar with the concepts of palliative care. Their thoughtful discussion of the holistic aspects of care of the dying suggests that a lack of knowledge would not prevent them from delivering good palliative care. Most participants also knew their local consultants in palliative medicine, yet many admitted to little idea of what they actually did. This may be because working practices are different in palliative care; the multidisciplinary team and the advisory nature of much of the doctors' work are better developed than in many other specialities. However, the strong perception that end of life care is a nursing role may mean that doctors fail to see the relevance to their own work.

The hospice movement has been a successful advocate for the development of holistic care of the dying. Palliative care has a place in many undergraduate and postgraduate curricula, and educators are now looking beyond the sharing of knowledge, to more effective ways of changing behaviour.[189;190] The study participants are likely to be typical of today's consultants and GPs, having had little or no formal training in palliative care. Whilst not lacking knowledge, they displayed attitudes that may prevent them from providing good palliative care. For example, the failure of death was discussed, as was the negative focus on survival within palliative care. For many doctors, the attitudes, beliefs, and self-perceptions that underpin professional practice may be potent barriers to holistic care.[185] This work suggests that greater emphasis on these within educational strategies may be beneficial. Perhaps most importantly, practical ways of applying what is already known are needed, rather than more theoretical research.

Summary

Participants displayed a reasonable grasp of the wider concept of palliative care, but the specialists' role was ill defined, reflected in scepticism about their place outside of cancer. Perceptions of palliative care fell into three broad areas: it was more than a service, about managing dying, and the concern of nurses, rather than doctors. Palliative care was welcomed as providing permission to fail, whilst representing a dilemma between quantity and quality of life for the interviewees. This chapter suggests that specialist palliative care has been partially successful in getting their message across, and poor understanding or receptivity are not major barriers to implementing palliative care. Educational or other interventions to implement change in palliative care need to acknowledge the complex interaction of factors influencing physicians' behaviour.

DISCUSSION AND CONCLUSIONS

This thesis has looked at the limited evidence for equity in end of life care, and used some new analyses to address related questions. In this concluding chapter, I review the findings and consider the implications for care of people with heart failure. Equity in palliative care has been recognised as a concern for the NHS, and the paucity of services for non cancer diagnoses was highlighted in a recent House of Commons Select Committee report.[191] However, I argue that what is needed for patients with conditions such as heart failure, is a general improvement in chronic disease management, rather than adapting services that were designed for cancer patients.

Summary of findings

End of life care for people with heart failure cannot be overlooked, and current care may not be optimal

The epidemiology of heart failure has marked it out as a growing issue for end of life care, and my analyses of mortality statistics and hospital episode data provide supporting evidence. Heart failure already represents a substantial part of the NHS workload. In the future, as a higher proportion of people survive heart attacks and life expectancies improve, more and more patients with heart failure will be dying in the community. The quantitative analyses carried out in this thesis suggest that the current care of people dying with heart failure may not be optimal. Patterns of hospital utilisation in the last year of life describe frequent admissions, some as emergencies, up until death. Analysis of routine hospital and mortality data by deprivation of area of residence indicated little variation in provision of services, despite great differences in predicted 'need' as measured by deprivation. Conceptually, provision may have been relatively equal, but not necessarily equitable, as it did not appear to be matched to need. Interpretation of this finding from the routine data is difficult, however, as detailed below, and requires more in-depth, individual level studies. Data from the focus groups showed that awareness of the needs of patients, and management strategies amongst health professionals are not well developed.

Some of the findings from both my quantitative and qualitative studies were echoed in research from Scotland by Murray and Boyd.[181;192] Interviews with heart failure patients and their professional carers described patterns of health service utilisation similar to that shown by my empirical studies. Intervention late in the disease course, and unpredictable emergency admissions were common. Medically focussed treatment was evident, suggesting that the Scottish health professionals had, like those in my focus groups in the north west of England, been able to give little time or thought to terminal heart failure care. The progressive decline of Scottish heart failure patients over time, with intermittent exacerbations and an unpredictable terminal state also accorded with the description of their own patients given by professionals in the North West. The similarity between the concerns of the Scottish patients and those anticipated by the north west doctors, reinforces the conclusions we draw from our findings, and suggests that this may be a more widespread issue beyond the immediate study area.

Implications

Much of the specialist care for people who are dying in the UK is provided by services focussed either on a health system or disease group, such as cardiology or oncology, or services defined by disease *stage*, such as palliative medicine. Certain services, such as the Macmillan nurses, combine these two factors, seeing patients with specific diagnoses (cancers), who are nearing the end of their lives.

For patients with cancer, accessing services by these routes presents relatively few problems. Referral pathways are well established, and health professionals have built up expertise in recognising and managing cancers at the different stages. Patients have expectations borne of the experience of family and friends, with a rich lay knowledge of cancer contributing awareness and support as well as the inevitable prejudice and fear. In contrast, patients with heart failure have neither well developed end of life networks to draw on, nor are they widely recognised as legitimate patients for palliative care. This thesis has begun to shed some light on the implications of this situation, but the overall picture is complex, rooted in historical development of health services in the UK and the challenging natural history of heart failure.

Access to services by stage of disease – the challenge of prognostication

If the terminal phase of heart failure is indistinguishable from previous exacerbations, impending death may be acknowledged late, if at all. Consequently, when access to a service is based on an awareness that the disease is near to the end of its course, patients with heart failure are sure to be disadvantaged. The unpredictable course of heart failure means that it is not feasible to define need for, or ability to benefit from a service by disease stage. Making a clear distinction between 'disease modifying' treatment and palliative care can be difficult for heart failure. Many symptomatic treatments are equally effective at improving prognosis.[35;36] Even if a patient with heart failure is classed as "terminal", acute interventions involving invasive procedures and intensive monitoring, may be needed to relieve symptoms such as acute pulmonary oedema. Clinicians treating heart failure face a dilemma, as the patients most likely to benefit from an intervention are the most severely ill, and probably closest to death. Judging when a patient with heart failure should be considered to be 'terminal' is a major challenge. Although much effort has been put into risk assessment for heart transplantation, accurate prognostication is still rarely possible.[193] This is not surprising, as doctors are relatively unreliable estimators of survival for cancer patients, where the course is more predictable at an individual level.[194] Survival estimates for patients with heart failure do appear to be much less accurate. In the USA, patients with heart failure admitted to hospice care tended to live, on average, six months longer after referral than cancer patients.[195] This phase of dying has been termed 'the middle muddle' – the approach of death has been recognised, but it is not clear whether the remaining time should be measured in weeks or months.[195] For patients with heart failure, the significant risk of sudden death adds to this uncertainty.

On its own, poor prognostication should not deny palliative care to heart failure patients. The founders of the hospice movement intended that the principles of palliative care should be applied from the time of diagnosis and continue after the death, for the bereaved. Initiatives such as cancer centres and networks have facilitated access to expert support at a very early stage of the cancer disease course, but the experience of palliative care for the majority of cancer patients is still much closer to death. Numerous deficiencies in the co-ordination of care for cancer patients have been highlighted in the recommendations of the National Institute for Clinical Excellence report 'Improving Supportive and Palliative Care for Adults with Cancer.'[196] It is likely that finite resources and competing pressures on clinicians' time have prevented early palliative care interventions from becoming a reality for cancer patients. The experience of heart failure care, which does not enjoy the same level of public awareness or financial support is likely to be even worse, particularly with the added complication of an unpredictable disease course.

Applying existing good practice, rather than inventing new services

I have highlighted the difficulties of applying cancer palliative care to heart failure. However, there are principles that could be usefully applied to terminal heart failure care. Most importantly, perhaps, is recognition that patients with heart failure do not require anything new from the health service. Care of the dying is already a mainstream NHS activity, present in the work of every discipline. The deficiencies in the care of heart failure patients may be easily remedied by what many would consider to be good practice in clinical care. Monitoring of patients so that they receive care in the appropriate setting and avoid unnecessary emergency admissions; communication between patient and professional over prognosis and treatment aims; looking at the social context for the patient and tailoring therapy to their expectations. These are part of good clinical management and do not require special training or further research to be implemented.

In public health, two approaches to preventive care have been described; the so-called high risk strategy, which targets individuals who are at high risk of developing a disease, and the population approach.[197] The latter describes the shift in a mean population level of a risk factor or behaviour, such as physical inactivity. This shifts the distribution curve for the risk marker, and results in a higher number of people in the desired zone than would be achieved by solely targeting those at high risk; in this example, taking more exercise. If this general approach is applied to end of life care, one could surmise that improving the average quality of care received by a patient with heart failure could shift the distribution curve, to produce a great population benefit overall. In other words, general changes in the management of chronic disease may therefore have the potential to improve the end of life experience for a greater number of patients dying with heart failure. This would avoid facing the challenge of identifying those heart failure patients with terminal care needs. The current haphazard targeting of heart failure patients known to be near death, represents a focus on high risk individuals, and possibly a lower overall health gain.

A continuum of care

Underlying this argument, is the concept that heart failure care should be considered along a spectrum, from support and monitoring in primary care to intensive inpatient therapy. At different times in the disease course, a modification in therapeutic goals may be needed. Palliative care would represent one of these 'changes in tempo' which could be reversed, rather than a final abrupt switch to purely supportive treatment. A palliative care approach certainly is compatible with excellent chronic disease management at any stage. A focus on symptoms, holistic care, incorporating the family in decision making: all of these are needed for the heart failure patient. However, some caution is needed with the label 'palliative,' as it may present barriers to both patients and practitioners.

The stigma of a terminal diagnosis was raised by the doctors in my focus group study. The ignorance of the poor prognosis and paucity of specific palliative care services for heart failure patients means the diagnosis does not have the same stigma as for cancer patients, and this was not a specific issue in recent qualitative work with heart failure patients.[192;198] However, the implications of palliative care are well known and may erect barriers for patients and their doctors. Professional attitudes towards palliative care may be a particularly important barrier to the development of appropriate end of life care. The perception that palliative care is the role of the nurse is prevalent, and thus it automatically assumes a low priority.[199] The elderly care physicians' discussion most clearly illustrated this point. Associations with cancer are strong, and may need to be actively countered. 'Caring', as one of the focus group participants said, is not glamorous, and if the specialities represented in this research are typical of their peers, many need to consider their broader role as carers if they are to meet the needs of their patient populations.

Professionalisation of end of life care has been rapid in recent years, with the formation of a specialty, and recent calls for 'primary palliative care.'[200] Although identification of a body of knowledge is the usual route to such a position, the sharing of skills and insight are central to specialist palliative care. This is one of the least tribal of the medical specialties, yet discussion of the need for primary care specialists may help to create an impression that end of life care is not an every day part of medical care. Most patients' problems at the end of life do not all require the specialised knowledge and training of the palliative care physician. The family doctor or hospital consultant will be providing appropriate care. As it is only primary care that offers care irrespective of diagnosis, prognosis or age, it seems obvious that general practitioners should have a central role. Much of the chronic disease management that is already delivered by GPs and district nurses could be termed palliative care. General practice offers continuity, a family orientation, and established multidisciplinary teams, which are central to palliative care.[201] In addition, patients repeatedly state their preference for GP care at the end of life, and this was reflected by the focus group participants and in the views of doctors from both primary and secondary care.[202]

Practical issues for primary care

This work has emphasised that the end of life with heart failure poses a number of practical challenges for primary care professionals. Time did not allow the focus group participants to explore all these issues in detail, but the discussion touched upon their lack of support. Palliative care is synonymous with a multidisciplinary approach, yet a general practitioner caring for the patient who does not have cancer may have a limited infrastructure to support him. Community staff must care for patients dying from a range of chronic diseases and with symptoms of varying complexity, giving them little opportunity to build up particular confidence or expertise with one specific diagnostic group. Such practical barriers need to be overcome before the patient with heart failure could expect adequate end of life care. Access to specialist nurse advice, welfare benefits, and appropriate in-patient care are all potential concerns. Knowing how to palliate end stage heart failure is probably less important, knowledge is easily acquired and the pharmacology of heart failure is changing rapidly. A recent systematic review affirmed the good performance of general practice in this area, but also identified a lack of confidence and poor support as the main problems.[203] There are few, if any, support groups specifically geared for heart failure patients, and little traditional published patient literature, so that the patients and professional carers may be relatively unsupported. Communication between health professionals, patients and carers may also be problematic in heart failure care. My focus group study and other recent work implies that patients with chronic heart failure may not know their likely prognosis, or even be aware of their diagnosis.[181;204] Discussion of prognosis, and preparation for death are thus compromised.

The level and quality of communication between cardiologists, other secondary care providers and general practice is fundamental to end of life care. Palliation is not the exclusive province of palliative care and general practice, but wherever that path is being taken, it is vital that all the professional carers are adopting a similar approach. This work has played an important part in producing evidence and bringing this issue to a wider audience.

Current initiatives

There are already a number of changes in progress within the UK NHS that may act to improve end of life care. Reorganisation of health services, to place primary care trusts in the role of commissioners and clinical governance leads, is one of the most important. The combination of GPs, and perhaps more importantly, nurses, in influential roles means that the importance of palliative care is likely to be better acknowledged. Through the NHS, practical help for clinicians has been presented with the Liverpool Care standards pathway,[191] and the Gold Standards Framework.[205] The former offers guidance and clear steps for doctors and nurses in settings outside of the hospice, to provide good basic palliative care. The Gold Standards Framework is supported by lottery monies, and Macmillan cancer relief. It offers advice and protocols for primary care teams to improve the organisation and management of primary care in the community. Although directed towards cancer patients, much is relevant to all patients and diffusion of good practice to other diagnostic groups could be expected. The unanswered question, brought into focus by my conclusions, is why is management of dying patients not an excellent service, if the solutions are so straightforward.

Limitations of the empirical studies

Generalisability

One of the major limitations of this work is the pragmatic need to focus on specific groups. Heart failure patients were chosen to be representative of people with chronic progressive diseases other than cancer, though the experience of both patient and health carer may be quite different in other diseases. Chronic obstructive pulmonary disease is the other leading common, chronic illness that causes death. However, the disease trajectory and clinical management challenges are very different to those of heart failure. Patients' understanding of their disease and prognosis may also differ quite significantly between these two groups. Society's response to illnesses, embodied in the personal and institutional attitudes to those affected, can have a profound effect on the individual patient's experience, and again will not be the same for every disease. Generalisation from this work to other diseases should, therefore be cautious. Some of the qualitative data have relevance to all patients. The perceived need to improve communication between health professionals caring for the same patients, or the efficient organisation of medical records, for example are findings that are independent of the disease under consideration. In contrast, the patterns of use of hospital resources by heart failure patients is peculiar to that group, and may not be mirrored by other chronic disease patients.

The exclusion of other health professionals from the focus group study was another way in which the study was limited to a particular group. Palliative care is unlike most other medical specialities in its emphasis on the multidisciplinary team. Whilst, in common with many other medical teams, the doctor usually takes a leading role, the autonomy and independence of some of the specialist nurses, and the acceptance of the important role played by others such as the alternative therapist, *are* different. In the community, in particular, care may be led by the specialist nurse, with relatively little involvement of the doctor. The focus groups participants were all doctors. Involving nurses and others in later groups was part of the original design, but this was removed as the work developed. The main reason was that it became clear that holding one focus group with nurses would not capture the range of experiences and views that were available, and risked being seen as a token gesture. Nurses will clearly play a major role in the development of non cancer palliative care. Their existing skills and current involvement suggest this, and the potential short fall of doctors in primary care will foster health service support for it. Their views and training needs are likely to be varied and complex, and, it was felt, merit a study in their own right.

'Patient centred' is a term found in many recent NHS documents. It reflects a changing relationship between doctors and patients, as medical mishaps or wrongdoing are better publicised, and the social status of the doctor diminishes. This study used data about patients' use of health services, but did not directly explore their experiences or views. This is a limitation, and that work remains to be done. My discussion of inequities presents a perspective developed from professional norms, which would have been strengthened by the collection of data directly from patients.

The qualitative work in this study was based in one NHS region. Professional practices are often shaped by influential individuals, and may be peculiar to a locality when there is no uniformity of service provision. In addition, many of the characteristics of the North West, where the work was conducted, do not necessarily reflect experience in the rest of the UK. Much of the area is urbanised, with some of the poorest electoral wards in Europe. Rates of coronary heart disease are high, whilst other indicators of morbidity and mortality describe a population far less healthy than the English average. The research design would have been stronger if the participants had represented different areas, but funding and practical considerations prevented this.

Shortcomings of routine data sources used in quantitative analyses

This work has neatly illustrated the many limitations of routine data. Death certification for heart failure is an imprecise measure, and the rules surrounding this merit review. It is still impossible to be certain that it is not the *mode* of death is being described on the certificate. The dataset describing use of services had many incomplete fields, which made the use of diagnostic information, for example, fruitless. For patients at the end of life, it is often the detail of care that is needed, and this is not found in a routine dataset. The reason for admission is crucial information to evaluate the use of services, but this is not the same as the diagnosis. Proper investigation of the appropriateness, quality and quantity of care at the end of life requires primary investigation. Similarly, social position was measured by area level deprivation in routine datasets. This means that the ecological fallacy cannot be avoided, and further reinforces the need for primary data collection.

Reflection on the qualitative methods used

(For consideration of quantitative methods used, see study IV.)

Focus Groups

Focus groups have been a tool in market research for many years, but their use in health care research is much more recent. Focus groups have been defined in many different ways, but most authors agree that they are group interviews, which feature organised discussion.[206] Focus groups have two features that distinguish them from other interview techniques. Firstly it is the interaction between the participants that generates the findings,[207] and secondly, the participants are 'focussed' on the same issue by a moderator. The issue may be a set of questions, or a collective activity, such as a film that is watched and discussed. The moderator's role is to lead the discussion, by guiding and probing. It is crucial that all the interviewees have views on, or experience of the subject to be discussed.[208] Their experiences are then explored during the focus group, through a set of defined research questions.

Focus groups are often used at the beginning of a project to generate ideas and plans for future research. For example, questionnaires or topic guides for more structured investigation have often been developed from focus group data. They also have a role in evaluation and review, at the end of a piece of work or pilot study.

The advantages of focus groups

Morgan's assertion that 'focus groups are useful when it comes to investigating what participants think, but they excel at uncovering why participants think as they do' is often cited as the most important advantage of focus group research. The interaction between interviewees can certainly produce more candour,[209] and allows an opportunity for views to be challenged and refined over the course of the interview. Thus, it is likely to produce a much more accurate picture of what people actually do and think,[208] with the data containing explanations, as well as descriptions.[206] If researchers are seeking group norms and the point of consensus, these are more readily revealed by focus groups than any other methods. The 'shared and variable perspectives' of participants are likely to be revealed by discussion.[210]

On a more practical level, focus groups are an efficient way of collecting data, taking much less time to produce a given amount of qualitative information than other methods.[211] They also provide an opportunity for the researcher to qualify questions, and pursue queries at the time of the interview.

Disadvantages of focus groups

The organisation of focus groups can consume a great deal of researchers' time, as arranging for a number of people to be in the same place at the same time may be particularly difficult. The running of the groups then calls for someone with interpersonal and leadership skills, who can control, challenge and shape the discussion. If this is done badly, the groups risk being a disorganised discussion, and the potential for one or more individuals to dominate is great.

Why focus groups were chosen for this subject

Focus groups were chosen as an appropriate method for this work, as little was known about how doctors view palliative care for non-cancer patients. It was likely that many of the participants had given little thought to this subject, and the focus group would present an opportunity to consider and formulate their views. The interaction between interviewees, in particular, was expected to facilitate this process. The series of focus groups was intended to be a pilot study for a larger, national study, generating data to inform the design of a structured survey instrument. Hence any lack of generalisability of qualitative work was not a limitation of the study.

Specific concerns relating to this work

The focus groups consisted of single speciality groups; either all general practitioners, or all doctors from one hospital speciality. The advantages of this approach was that the participants had a shared understanding of each others work, and some of the initial stages of a focus group, where trust is built up, were rapidly overcome. This combination also minimises the potential for disruptive power relations between the interviewees. Had the groups been mixed between GPs and consultants, it is possible that perceptions of a higher status amongst hospital doctors may have prevented their GP colleagues from expressing themselves honestly. Potential disadvantages of not mixing the specialities included the possibility that the interviewees would have a uniform view on some issues, and there would be few challenging voices. Conforming to group norms could be especially evident amongst what is an inherently conservative group.

Future research

At least three questions arise out of the qualitative work with doctors, presented in study V. Firstly, too little is known about the needs of heart failure patients in their last year of life. In order to develop effective services, the factors that determine quality of life as people with heart failure approach death need to be elucidated. In particular, examination of the ways in which heart failure and cancer patients differ will help to determine how existing palliative care services need to change.

Secondly, the question of how palliative care should be delivered to heart failure patients is unresolved. There appears to be a great deal of support for developing a role for specialist nurses. Whether specialist palliative care nurses should be trained to care for patients with heart failure, or heart failure nurses trained in palliative care, is an important question. The nature of such additional training has also yet to be determined.

The quantitative study strongly suggests that the health service should consider alternatives to the use of acute hospital beds for patients dying with heart failure. Economic analyses would strengthen the case, but the bed utilisation figures alone paint a picture of potentially inappropriate use of resources on a large scale.

There is a paucity of research in palliative care that considers the association between the socio-economic status of the patients, or the area in which the services are based, and the provision of, or access to care.[212] As terminal illness undoubtedly has social and financial consequences, any inequities in services may exacerbate existing social inequalities. This thesis employed routine hospital and mortality data to explore the link between palliative services and area deprivation, but the questions that can be answered from these data are limited. To go deeper and gain an understanding of differential social and economic consequences require different data sources, ideally including individual level data on patients from different socioeconomic groups in the last year of life, followed longitudinally. This is the area of research I will take forward with Medical Research Council funding: exploring social patterning in the consequences for the household that cares for someone who is dying.

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APPENDICES

Appendix 1. Methods and search strategy for literature review

Methods

Literature in English was identified through searching of electronic databases (Medline, Embase, PsychLit, Social Science Citation Index). The search strategy is shown below. Relevant journals were also searched by hand from 1990 (where available) to date (Palliative Medicine, Journal of Palliative Care, Journal of Pain and Symptom Control, British Journal of General Practice). Specific searches were made for authors known to have published in this research field (Higginson, Addington-Hall, Lynn, Cartwright). Websites of charities and other organisations associated with end of life care were also scrutinised (Help the Hospices, Macmillan Cancer Relief, Marie Curie Cancer Care).

No study designs were excluded, and all relevant material was reviewed, including opinion pieces and review articles. As the output is a narrative synthesis, no formal data extraction procedure was employed. The studies were categorised by the particular barrier posed to equitable access to end of life care; ability to pay for services, ethnic origin, age and gender.

Search Strategy

Terms relevant to end of life care, access, equity and socioeconomic status were combined for searching of electronic databases. Published search strategies were adapted wherever possible.[204]

Terms relevant to end of life care

Exp Palliative care/ all subheadings
Exp Terminal care/ all subheadings
Hospices or hospice-care/ all subheadings
Exp oncologic nursing/ all subheadings
Exp cancer-care-facilities/ all subheadings
(Nurs* or carer* or caring or hospi* or team* or death or dying or service* or need* or demand* or famil* or health or policy or model* or delivery or evaluat* or program* or utili?ation or organi?ation or home or preference* or co?ordinat* or effect* or role or quality or support)
Hospices/economics, manpower, organization and administration, supply-and-distribution, statistics and numerical data, standards, trends, utilization)

Terminal-care/economics, manpower, organization-and –administration, supply-and-distribution, statistics-and-numerical datastandards, trends, utilization
Palliative-care/economics, manpower, organization-and-administration, supply-and-distribution, statistics-and-numerical data, standards, trends, utilization

Terms relevant to socio-economic status and access to care:

socioeconomic factors/ or poverty/ or poverty areas/ or social class/ or social conditions/ or educational status/ or employment/ or unemployment/ or family characteristics/ or marital status/ or income/ or medical indigency/ or poverty/ or social conditions/
health services accessibility/
(equit$ or inequit$ or inequal$).mp.
(access$ or inaccess$).mp.
((service adj utilisation) or (health adj service adj utilisation) or (health adj service adj us$)

In addition, specific searches were made for material relating to ethnic minority care and palliative care education.

Appendix 2. Multivariate Analysis

Assessment of outliers and influential variables

An outlier is a data point that does not fit the trend suggested by the rest of the data. They may be mistakes in the data, unusual values, or a sign of violation of model assumptions. Outliers can be seen visually in the scatter plots, but they are also identified by large standardised residuals. (95% of standardised residuals should lie within the range +2 to -2 if errors are normally distributed). However, outliers tend to increase the value of the standard error of the estimate, which is used to calculate the denominator in the standardised residual. This means that the standardised residual will increase as the standard error of the estimate increases. A large residual and a large denominator may allow an outlier to go unnoticed. Studentised deleted residuals are produced by SPSS. These are based on a calculation of the standardised error of the estimate with and without a deleted variable. If the value was an outlier, the SE will be smaller without it.

When an observation is suspected of having a great influence on the results of the regression, the leverage may be calculated. This measures how far the values of the independent variable are from their mean values. As high leverage may not necessarily be associated with great influence in the regression equation, SPSS calculates Cook's distance to identify influential observations. This uses both the residual and the leverage to determine whether an observation is influential. Values of Cook's distance > 1 should be looked at more closely.

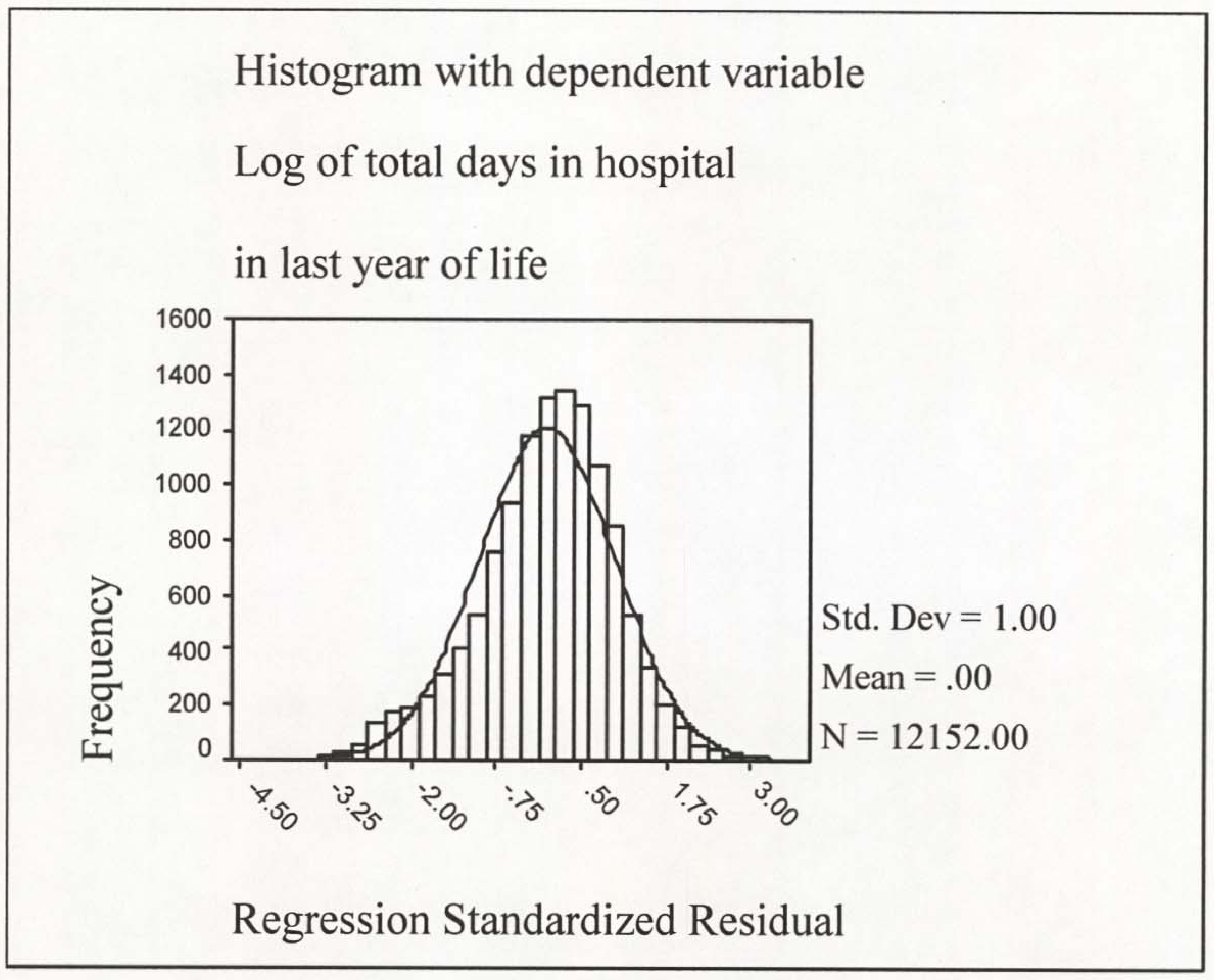
Heteroskedasticity

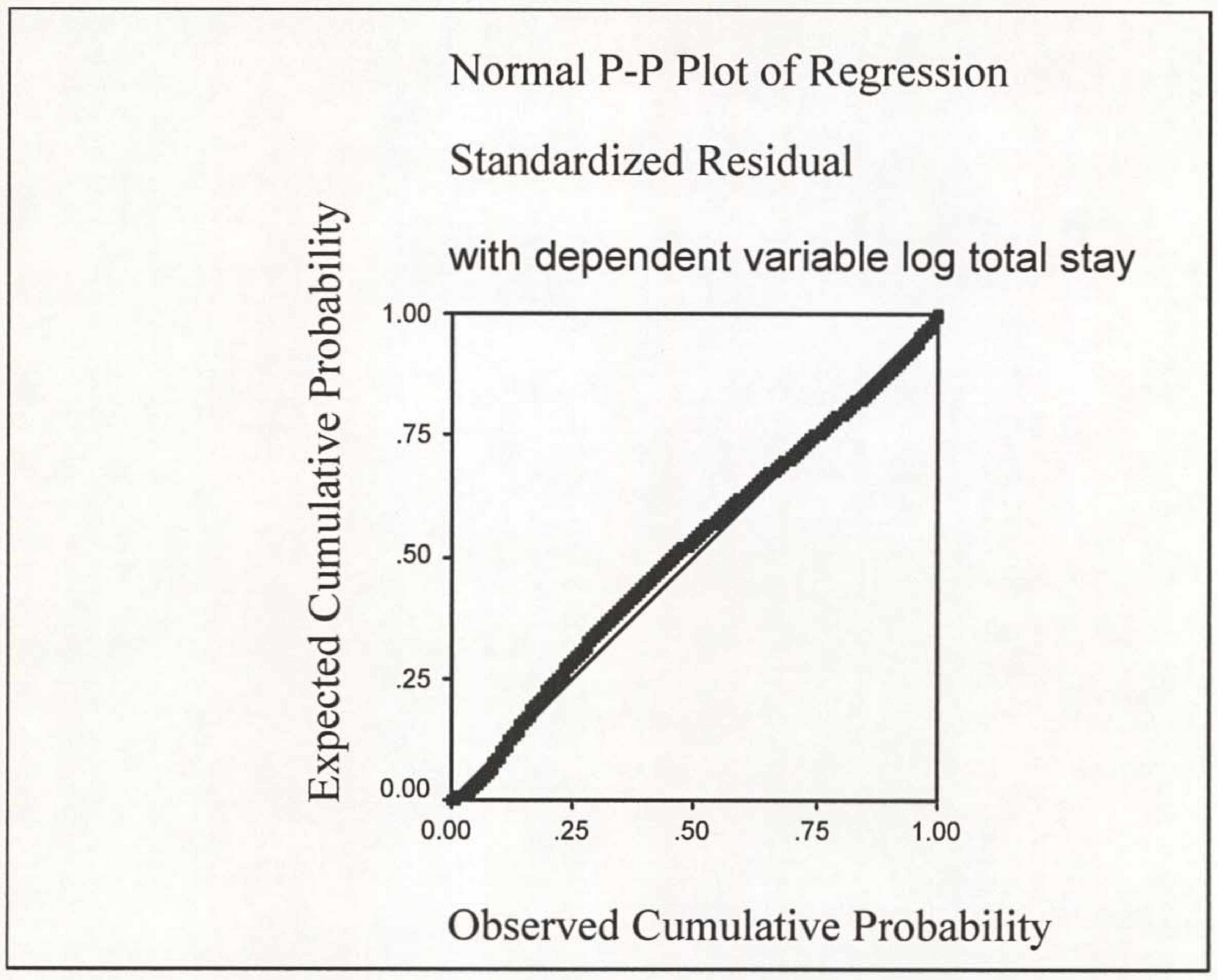
The scatter plots (not shown) and other residual plots (Appendix 3) suggest that the error variances are normal, and no formal tests for heteroskedasticity were conducted.

Multicollinearity

The variables do not appear to be highly correlated, as the correlation coefficients between the variables are low, and none are above the widely used cut off value of 0.7. This suggests that all of these variables may be providing additional information to the regression equation. Low *t* ratios and wide confidence intervals for the coefficients, which would also raise the suspicion of multicollinearity are also not seen. SPSS produces variance inflation factors. This measure has many limitations, but in this case it is helpful in confirming the absence of significant multicollinearity. (The variance inflation factor, (VIF) ($\beta\hat{}$) = 1 / 1-R_i^2 Where Ri^2 is the squared multiple correlation coefficient between a variable x and the other explanatory variables. In other words, VIF compares the actual variance of $\beta\hat{}$ to what it would have been if x is not correlated to the other explanatory variables. The VIF values are all close to 1, which also supports the argument that multicollinearity is not a major concern.

Appendix 3. Regression analysis: goodness of fit of the model





Appendix 4. Published papers

The following papers and book chapter have been published or accepted for publication, based on study V and a section of the literature review:

Hanratty B, Hibbert D, Mair F, May C, Ward C, Capewell S, Corcoran G. Doctors' perceptions of palliative care for heart failure: focus group study. British Medical Journal 2002;325(7364):581-585

Hanratty B, Hibbert D, Mair F, May C, Capewell S. Doctors' understanding of palliative care. Palliative Medicine *in press*

Hibbert D, Hanratty B, May C, Mair F, Litva A, Capewell S. Negotiating palliative care expertise in the medical world. Social Science and Medicine 2003;57(2):277-288

Whitehead M, Hanratty B. (2004) Health care for rich and poor alike. In Healy J, McKee M. (Eds) Accessing health care: Responding to diversity, pp71-88. Oxford University Press, Oxford.

Three further papers based on studies II – IV and the background section have been submitted for publication.

Dissemination:

This research has been presented within the University of Liverpool and at the North American Primary Care Research Group Annual Meeting, Halifax, Canada 2002, the Association of University Departments of General Practice Conference, Leeds 2002 and the Society for Social Medicine Annual Scientific Meeting, Oxford 2002.

The findings of the focus group work contributed to recent national policy discussions on palliative care for non-malignant conditions, through the palliative care consultant in my research advisory team.

Doctors' perceptions of palliative care for heart failure: focus group study

Barbara Hanratty, Derek Hibbert, Frances Mair, Carl May, Christopher Ward, Simon Capewell, Andrea Litva, Ged Corcoran

Abstract

Objectives To identify doctors' perceptions of the need for palliative care for heart failure and barriers to change.
Design Qualitative study with focus groups.
Setting North west England.
Participants General practitioners and consultants in cardiology, geriatrics, palliative care, and general medicine.
Results Doctors supported the development of palliative care for patients with heart failure with the general practitioner as a central figure. They were reluctant to endorse expansion of specialist palliative care services. Barriers to developing approaches to palliative care in heart failure related to three main areas: the organisation of health care, the unpredictable course of heart failure, and the doctors' understanding of roles. The health system was thought to work against provision of holistic care, exacerbated by issues of professional rivalry and control. The priorities identified for the future were developing the role of the nurse, better community support for primary care, and enhanced communication between all the health professionals involved in the care of patients with heart failure.
Conclusions Greater consideration should be given to the care of patients dying with heart failure, clarifying the roles of doctors and nurses in different specialties, and reshaping the services provided for them. Many of the organisational and professional issues are not peculiar to patients dying with heart failure, and addressing such concerns as the lack of coordination and continuity in medical care would benefit all patients.

Introduction

Heart failure is a common condition; estimates of prevalence range from 2 to 10 per 1000 population, and the incidence is rising as more people survive acute coronary events.[1] The median survival for heart failure (16 months after first hospital admission, unadjusted) is worse than for many of the common cancers.[2] Despite this poor outlook, those who die of the condition in the United Kingdom seldom access specialist palliative care services, and responsibility for their care lies with primary care, cardiology, geriatrics, or general medicine. Palliative medicine grew out of the hospice movement, and cancer charities still make a substantial contribution to the costs of palliative care. This, coupled with professional doubts over the wisdom of expansion, means that specialist care of the dying is virtually synonymous with cancer care in the United Kingdom.[3]

In recent years, however, there have been calls to recognise the needs for palliative care of people with heart failure.[4–6] The national service framework for coronary heart disease endorsed this view but failed to address the question of how it should be provided or to identify new sources of funding.[7] As the research evidence for unmet needs of care in terminal heart failure grows, it has not been accompanied by investigation into appropriate models of care.[6–8] Patients dying with heart failure may have unpredictable illness trajectories; understanding and expectations will also be different to patients with terminal cancer. The needs of health professionals for support and experience with palliative care for heart failure are also likely to vary. Box 1 suggests aspects of palliative care that may not be readily available to patients with heart failure.

In the absence of an evidence base, doctors' views on terminal care for patients with heart failure are likely to be influential in shaping the development of future care. In our study we used focus groups to explore doctors' views of palliative care for patients with heart failure, and we aimed to identify barriers to improving the care of this patient group.

Participants and methods

Our study was exploratory owing to the paucity of research, therefore focus groups provided an appropriate approach. Apart from being an efficient means of data collection, focus groups allowed the participants to use their own frames of reference and to identify the topics that were important to them. Clarification of views through discussion and debate was particularly valuable for a topic to which the participants may not have given much prior consideration.

Sampling

We recruited seven specialty groups of doctors; two each of general practitioners and consultant cardiologists and one each of consultants in geriatrics, general

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BMJ 2002;325:581–5

Box 1: Aspects of palliative care that may not be available to patients with heart failure

Services

- Multidisciplinary support in the community[5,7]
- Specialist nurse practitioners[9,10]
- Access to inpatient beds for palliative care
- Professional carers trained in the principles of palliative care[5]
- Social and financial support comparable to that of patients with cancer

Approaches

- A strategy for a timely move from invasive treatment to supportive care[5]
- Optimisation of treatment of the underlying disease[4]
- Improved symptom control[4] and attention to comorbidities
- Emphasis on quality of life[4]
- Discussion of prognosis[8] early in the course of disease, seeking patients' views[5]
- Acknowledgment of disease specific barriers to effective communication[8]
- Adequate information for patients[11]

medicine, and palliative medicine. These were chosen to reflect the specialties that are most concerned with patients with heart failure. We included doctors from tertiary referral centres (one cardiologist group), teaching hospitals, and district general hospitals to ensure access to a wide range of views. One general practitioner group was made up of doctors with either a teaching or research post at a university. We took a pragmatic approach to recruitment, and participants were found from several different sources, depending on circumstances (table).

Data collection and analysis

The focus group meetings lasted an average of 80 minutes. We developed a topic schedule to address our aims, using published literature and our own experiences. The groups were also encouraged to raise their own issues. The same facilitator and observer attended all the meetings, which were tape recorded and transcribed. These two researchers then coded all the transcripts with Nvivo software.[12] The data were analysed by using the principles of constant comparison.[13] The tapes were scrutinised before examining the transcripts and for checking of final interpretation. Emerging themes and categories were identified independently, and agreement was reached by discussion. The researchers were from different disciplines, and only one had prior knowledge of the area of research. The reliability of the findings was enhanced further by scrutiny from the steering group, which included practising clinicians.

Recruitment and participants

Group	No in group (No male)	Method of recruitment
General practitioners	5 (4)	Written invitation to practices in one area, allied to research consortium
General practitioners (teaching and academic)	5 (4)	Written invitation to doctors employed by one university
Cardiologists from district general hospitals	5 (4)	Written invitation and telephone calls to cardiologists in hospitals in one region
Cardiologists from tertiary referral centre	3 (3)	Introduction by member of study steering group, written invitation and telephone calls
Geriatricians	6 (5)	Introduction by local secretary of the British Geriatric Society, written invitation plus telephone calls
General medicine doctors	4 (2)	Written invitation and telephone calls to physicians at hospitals in one area
Palliative care doctors	6 (1)	Introduction via member of steering group, held after subregional meeting

All hospital and palliative care doctors were NHS consultants.

Results

Organisational barriers

The workings of the system were a concern for many of the hospital doctors (box 2). Care for patients dying with heart failure was described as uncoordinated, with patients going from hospital to community and back again. Repeated admissions to different consultant teams were common, and patients' medical notes were sometimes said to arrive on the wards after the patient had been discharged or died. A picture emerged of poor quality care for the patients and frustration for the doctors. The lack of continuity in current medical practice was highlighted by the geriatricians and palliative care doctors. All the groups thought that poor support in the community contributed to repeated hospital admissions. Adequate basic services, such as district nurses and social services, were a higher priority than more sophisticated forms of palliative care. Although hospital colleagues empathised with the general practitioner struggling to cope without support, the palliative care doctors and cardiologists were also concerned about the impact of the quality of care provided by general practitioners.

Box 2: Organisational barriers

And there are no proper links between our management structures and the community management structures, and this lack of seamlessness in the management of these patients needs to be dealt with. The trouble is because the consultants are managing patients in isolation when they're on the wards and the general practitioners are trying to manage them at home, they're falling between two stools, and that seems to me to be a real problem. (Tertiary centre cardiologist 2)

I think it's something that's been lost in modern medicine, the continuity of care and not just in heart failure, across the board. I mean I'm ashamed of the way we treat patients in our hospital. You can be discharged on a Monday; you can be readmitted on Wednesday. (Geriatrician 5)

Implicit in the discussions was that care for people dying with heart failure had not been planned. This was most clearly expressed by the cardiologists, who acknowledged the need to develop those formal and informal connections between specialties that are essential to coherent care. All the groups suggested that different models of care in the community might be needed. The concept of a key worker was raised as a possible solution by both general practitioners and cardiologists. This is a model seen in psychiatry, whereby a member of the team coordinates and oversees the care received.

Box 3: The course of heart failure as a barrier

But even when you're at the very end and it's the last few weeks, you still don't know whether they're going to just die suddenly now or whether over the next few weeks they're just going to gradually drift away. So that does make it more difficult in trying to prepare them and their relatives for what's actually going to happen. (Cardiologist 3)

It's very difficult, you can't really say who's going to recover ... you know sometimes they respond and sometimes they don't. So it's this sort of roller coaster type of thing and it's very difficult to give a prognosis other than "well it's his heart, it is serious you know." (General practitioner 3)

Prognostication

Unlike with cancer the diagnosis of heart failure does not begin with bad news, and when to initiate palliative care is a difficult question that was discussed by all the groups. The path of chronic heart failure is unpredictable, with half of patients dying suddenly (box 3). Stories were told of patients being admitted near to death and being "pulled back from the brink." Other patients were perceived as being quite well but able to switch to being terminal rapidly.

The uncertain prognosis of heart failure meant that doctors were concerned about the impact on the patients of giving bad news too soon. This was termed the "therapeutic and anti-therapeutic" use of prognostication by one general practitioner, and it generated different concerns in the groups. The major fear of the cardiologists was saying the wrong thing and the patients "losing faith" in their professional carers, whereas the general medicine doctors did not want to see the patients give up the fight for life. The wider implications for the family and carers were raised by the general practitioners.

Increasing openness about prognosis brought with it growing demands on doctors, and patients were thought to need a lot of psychological support. Doctors in all groups portrayed themselves as bad prognosticators, admitting that they may accept the poor outlook late in the illness. Patients, carers, and nurses were all suggested as more realistic predictors. As the beneficial effects of open communication in terminal care were acknowledged, this may have represented an unwillingness to engage with difficult issues.

Doctors' roles

Although many participants agreed that the general practitioner is a central figure in palliative care for heart failure, there was some questioning of the appropriateness of the involvement of specific groups. The most severe criticism was reserved for the cardiologists, who were charged by all groups with failing to recognise palliative care needs or practise holistically. In contrast to their colleagues' image of them, the cardiologists articulated an approach supporting teamwork, common goals, and a willingness to involve whoever had the appropriate skills. They also seemed to place most importance on dialogue between the specialties to improve care in the future. The palliative care doctors were generally viewed favourably by their colleagues, although the need for their specialty was questioned by some general practitioners, who felt able to manage their own dying patients. For these general practitioners, the palliative care specialists were inaccessible or liable to "steal" the general practitioners' patients. The general practitioners saw themselves at the centre of things, both providing and coordinating care. This was echoed by the geriatricians, who argued for care provided by community services, supported by others (box 4). The perceived inability of palliative care doctors to manage heart failure competently and the unwillingness of cardiologists to provide palliative care were used to justify this approach.

Box 4: Roles

I mean I haven't come across a palliative care physician yet who's comfortable in treating heart failure. So I'd have said that it should be the physician who's interested, the general practitioner, the district nurse .. if they're heart failure nurses, well great ... I really think [specialists in palliative medicine] should, instead of further fragmenting the service, go back to supporting the primary care team, the general practitioner, and the district nurse. (Geriatrician 1)

I think one needs to meet with the two specialties [cardiology and palliative medicine] to work the thought and processes through a bit . . there's too much of a gap between ... the way I practise and what I vaguely perceive is available on the other side. And I'm trying to reach out every so often for specific patients to be supported, and partly it's my lack of knowledge and uncertainties as to what to call for, that's holding things back. (Cardiologist 2)

The future

Our participants invested some hope in the national service framework as a means of increasing funding in palliative care for heart failure. A need for discussion and links between specialties was acknowledged chiefly by the cardiologists. In contrast, all the groups talked at some length of an enhanced role for nurses (box 5). The nurse was seen as a figure who could follow patients into the community after discharge from hospital, liaise between primary and secondary care, ensure that treatments were adhered to, and mobilise appropriate support.

Discussion

Greater consideration is needed towards the care of patients dying with heart failure, clarifying the roles of

Box 5: The future

Specialist nurses that ... will keep a focus on the whole picture. And where that individual then goes or whether they're admitted or not, [the nurses] can then pick it up and coordinate the service so that the total global picture is kept in focus. So that should be ... relatively easier to notice a trend and then intervene with a palliative care approach at a more appropriate stage. (Geriatrician 4)

I see her [the heart failure nurse] facilitating or passing on her expertise to the primary care team and saying ... this is the programme I want to follow for the next few days, if it's not working give me a bell. (Geriatrician 5) health professionals in different specialties. Doctors in our study did not dispute the place of palliative care for patients dying with heart failure. However, we identified important potential barriers to the development of a palliative care approach to this patient group. These barriers arose from three main areas: the organisation and delivery of services, the course of heart failure, and doctors' views of their colleagues' roles.

Strengths and limitations

From the outset our study was intended as a forerunner to research with nurses, patients, and other groups across the United Kingdom. Doctors were chosen as a starting point because of their role in shaping demand for services. However, we acknowledge that a study involving one professional group cannot expect to generate anything other than cautious conclusions about a multidisciplinary subject such as palliative care.

Our study was novel and made appropriate use of focus group methods to generate issues for further investigation. Our pragmatic approach to recruitment is justified by the pressures on clinicians' time and low response rates to research studies. However, as participants in our study gave their time voluntarily, it is likely that they were more motivated and interested than average. By using single specialty groups we aimed to minimise the impact of power relations between the interviewees and to limit the disparity between their public and private accounts. The data were analysed by a medically qualified doctor and an experienced qualitative researcher. The high level of agreement between the themes generated independently by researchers with different perspectives increases our confidence in the results.

The findings point to the need for health professionals to give greater thought to the care of patients dying with heart failure, clarifying the roles of doctors and nurses in different specialties and possibly reshaping the services provided. Clearly, these are the priorities of doctors, and they may not reflect accurately the patients' experiences. Investigations into the concerns of patients dying with non-cancer diagnoses have tended to focus on the impact of the disease on the individual, rather than organisational issues.[8 14 15] However, patients with heart failure have been shown to have worse access than patients with cancer to a range of community services, even when attending a dedicated clinic. These patients also identified a need for their professional carers to improve their dialogue with each other.[16] Prognostication in heart failure is particularly uncertain, but other problems are shared by patients with chronic progressive conditions. Studies of patients with chronic obstructive pulmonary disease have highlighted similar lack of continuity in care and the need for a more holistic approach.[17 18] Communication with doctors is a common source of dissatisfaction for patients of all diagnoses needing palliative care.[8 19 20]

Implications

Our participants gave graphic descriptions of the inability of the National Health Service to deliver what they saw as an acceptable level of care to this patient group. Many of the issues they raised were not specific to the care of heart failure, or even to end of life care. Correcting such a failure of the system and challenging attitudes that inhibit collaboration are long term goals. In the short term it is likely that practical solutions for some of the component problems would improve the lot of patients dying with heart failure. Greater use of information technology could ameliorate some of the organisational deficiencies described, for example. Most of the doctors in our study were enthusiastic about developing the role of the nurse in terminal heart failure. They described an often superior ability of the nurse to liaise with other specialties and to communicate with the patients. Underlying this is a dilemma often seen in general practice, that of balancing a desire to maintain ownership of an area of care, with existing heavy workloads. The solution proposed goes some way towards avoiding the competing claims to holism among medical specialties. A nurse with expertise in cardiac palliative care is ideally placed to act as a coordinator of services, as well as influencing medical practice. However, delegation, rather than empowerment, does not remove the question of which specialty should take the lead. In recent years several nurses have been appointed to work with patients with heart failure, usually attached to a hospital cardiology centre. Research suggests that specialist nurses may reduce the number of hospital readmissions and improve disease management for patients with heart failure discharged back to the community.[9 10] A role in palliative and terminal care has yet to be defined, although specialist palliative care nurses such as those from the Macmillan service provide a successful model that could be adapted.

As the palliative care needs of patients with heart failure are acknowledged, the demands on health and social care services in the community are likely to

What is already known on this topic

Patients with heart failure have unmet needs for health care at the end of life

Specialist palliative care services see few patients with heart failure

The national service framework for coronary heart disease endorses the provision of palliative care for heart failure

Little evidence exists on how this care should be provided, and doctors' views are not known

What this study adds

Barriers to adopting a palliative care approach in heart failure care relate to the current organisation of health services, the difficulties of prognostication, and doctors' understanding of roles and responsibilities

Doctors believe that the general practitioner should be the central figure in palliative care for heart failure, supported by specialists

Doctors' future priorities are developing the role of nurses, increasing essential community services, such as district nursing, and improving communication with colleagues increase. Furthermore, there is growing recognition that palliative care services need to be integrated into primary care.[21] Recent changes in the NHS, such as the introduction of joint commissioning by health and social services and the development of primary care trusts, may, in the long term, herald a more favourable attitude to developing community support for patients with heart failure. While primary care trusts are in their infancy it may prove difficult for them to innovate and develop services. Although primary care trusts are to control about three quarters of the NHS budget, they are immature organisations, with unproven processes and inexperienced staff.[22] It also seems unlikely that palliative care for heart failure will be a high priority compared with many other targets that are explicitly highlighted in national service frameworks. However, with the prevalence of heart failure increasing, planning for the needs of people dying with heart failure in the NHS must become a priority issue.

We thank the participants.

Contributors: BH had the idea for the study, collected and analysed data, and wrote the paper; she will act as guarantor for the paper. DH contributed to the study design, collected and analysed data, and helped to write the paper. CM assisted with the conception and design of the study, supported the interpretation of data, and contributed to drafting of the paper. FM supported the organisation and management of the project and contributed to the study design, data interpretation, and writing of the paper. SC supported the organisation of the project, study design, and data interpretation and commented on drafts. CW helped with the study design, supported data collection, and commented on drafts. AL assisted with the development of the study and data interpretation and approved the final draft. GC assisted with the conception and study design and recruitment of participants and commented on drafts.

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A memorable message

It was the monthly meeting between clinicians and management. It had been going on for three quarters of an hour. The discussion was disjointed and downbeat. Colleagues were sad and disappointed by the effects of the latest round of NHS reorganisation on clinical services. Since 1974 the psychiatric services for Neath, Port Talbot, and Swansea had been integrated. This was successful. It was now to be broken up to recreate the pattern seen before 1974. In future, Neath and Port Talbot would be reintegrated with Bridgend.

Our meeting was starting to go round in circles, mirroring planning in the NHS. At this point I looked to my left. My young colleague, who had been listening intently, was now doodling, and this was taking up most of her concentration. A picture of a lighthouse or a beacon was emerging.

Clearly this was a message from the unconscious that our discussions lacked focus. The meeting needed direction and a firm steer. I brought this to the attention of my colleagues, who could see how apt it was. The intervention was successful, and we began to think more positively about the way ahead.

As medicine becomes more "scientific," the art of being a good doctor is marginalised. This example reinforces the need to maintain the more subtle intuitive skills in our work. It is still worth reading Freud's *Psychopathology of Everyday Life*, an interesting account of common mental mechanisms.

D D R Williams *consultant psychiatrist, Cefn Coed Hospital, Swansea*

We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to.

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Negotiating palliative care expertise in the medical world

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Abstract

This paper explores the relationship between palliative medicine and the wider medical world. It draws on data from a focus group study in which doctors from a range of specialties talked about developing palliative care for patients with heart failure. In outlining views of the organisation of care, participants engaged in a process of negotiation about the roles and expertise of their own, and other, specialties. Our analysis considers the expertise of palliative medicine with reference to its technical and indeterminate components. It shows how these are used to promote and challenge boundaries between medical specialities and with nursing. The boundaries constructed on palliative medicine's technical contribution to care are regarded as particularly coherent within orthodox medicine. In contrast, its indeterminate expertise, represented by the 'holistic' and 'psychosocial' agendas, is potentially compromising in a medical world that prizes science and rationality. We show how the coherence of both kinds of expertise is contested by moves to extend palliative care beyond its traditional temporal (end-of-life) and pathological (cancer) fields of practice.

Keywords: Palliative medicine; Palliative care; Nursing; Inter-professional relations

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Introduction

The UK hospice movement was set up to foster new and potentially challenging approaches to the care of people dying from cancer (Clark & Seymour, 1999; Seale, 1998). The inspirational foundations of the movement have been described as being 'essentially creative and disruptive' in relation to existing service provision (James & Field, 1992). Part of the challenge to orthodox medical practice lies in the espousal of a 'holistic' model of care;

> Palliative care is the active total care of patients whose disease no longer responds to curative treatment, focusing on the quality of life and integrating the physical, psychological, spiritual and social aspects of care (National Council for Hospice and Specialist Palliative Care Services, 1995)

From the mid-20th century in the UK the number of in-patient hospice facilities grew slowly, many of them funded with charitable monies. Later, more and more emphasis was placed on developing multi-professional teams to work in other settings. Now, all areas of the UK have a palliative care service with varying combinations of specialist nurses, doctors and other professionals working in the hospital, hospice and community. A distinction may be drawn between these specialist services, delivered by trained personnel, and a 'palliative care approach'. The latter emphasises holistic care of the patient, and is seen as having wider relevance for clinical practice in general.

Palliative Medicine was recognised as a medical specialty in 1987 by the Royal College of Physicians. Hospice doctors thus became eligible for consultant status, in the same way as surgeons or physicians. Some writers have questioned whether the evolution of the

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independent hospice movement into specialist palliative medicine within the National Health Service has 'compromised' the founding principles of palliative care (for a review of this debate, see Clark & Seymour, 1999, pp. 105–124). Since palliative care specialists are required to interface with other specialties in their work, care must be taken to ensure that palliative care 'complements' general medical care (Costello, 2001, p. 214). Thus, as hospice principles are absorbed into mainstream health systems, they may be subject to dilution from the medical emphasis on physical interventions and traditional professional hierarchies.

In this paper we show some of the ways that palliative care is currently functioning 'within the walls' of the modern health service, and how its distinctiveness is both promoted and challenged. Our focus is on the work of doctors, and we use the term 'palliative care' to indicate both the service they provide as individuals and their role within a multi-disciplinary approach to care. The paper is based on a series of focus group discussions with doctors from different medical specialties, which was set up to explore their views of developing palliative care for patients with heart failure.

The study was prompted in part by recommendations that specialist palliative care should be more widely accessible for people with a non-cancer diagnosis. This proposal is beginning to find its way into UK National Health Service policy. For example, a series of National Service Frameworks (NSF) is in development, which outlines service 'specifications' for various medical conditions and patient groups. It is a specific, though unelaborated, recommendation in the NSF for coronary heart disease that palliative care should be considered for people dying from heart failure (Department of Health, 2000a). The doctors in the focus groups discussed the professional issues arising from this proposal.

Study and method

As the studies described in Barbour and Kitzinger (1999) suggest, focus groups have tended to be used in health and social research to access the accounts of the relatively disenfranchised, such as minority groups and service users. We have used them here as a means to understand the views of relatively powerful and articulate health professionals. We conducted seven focus groups in the North West of England with doctors involved in the care of people dying with heart failure. The groups were single-speciality and comprised general practitioners (two groups, one of GPs with academic appointments), consultants in elderly care, cardiology (two groups, one each of secondary and tertiary care cardiologists), palliative care and general medicine. While all participants in the study were doctors, the specialties involved differed in terms of their sphere of practice (primary, secondary and tertiary care), their generalist/specialist orientations and in the length of time they have been established. We chose to use single specialty groups because we expected there to be hierarchical relations between the specialities that might inhibit expression of views. Discussing an area of care that involves many different disciplines with one professional group, albeit one with considerable influence on the services provided, has obvious limitations. However, we felt that to explore adequately the views of nurses, for example, would require a number of additional groups. This was not possible within the resources available to us.

To hold the focus groups, we took advantage of existing professional meetings, and some were held at lunchtime in the hospitals where participants worked. Working relationships between participants were therefore already established in many cases, and this may have contributed to their apparent familiarity and comfort with the group context. We note in passing that the participants did not explicitly question, or find difficulty with, the qualitative nature of the focus group methodology. The moderator (DH) and observer (BH) were the same for each group, and the format for each group was broadly similar, beginning with introductions and some background to the study. We referred to the NSF for coronary heart disease and the proposed provision of general or specialist palliative care for people dying from chronic heart failure. The starting point was a question asking the participants what they understood by the term 'palliative care'. The scope of discussion that followed was determined partly by a topic guide, which covered the following; views of current and ideal services for patients with terminal heart failure, communication and professional boundary issues and views of patient/carer involvement. The general aim was to keep group moderation to a minimum, and allow participants room to express what was important for them. In practice, all of the discussions except one were fairly self-sustaining. There was less group interaction in the General Medicine group, and the moderator took a more active role than usual.

Analysis of data

Transcripts were checked for accuracy against the audiotapes. After listening through the tapes, the two researchers (a clinician and a social scientist) who were present in all the groups coded the transcripts independently using computer software. The transcripts were coded in their entirety, and similar coding headings were then merged or grouped together, with some hierarchical organisation. There were differences in approach between the researchers, the main one being that (BH) began with a more developed coding framework, perhaps reflecting prior immersion in the palliative care field. The two researchers met formally three times to discuss the findings and compare emergent category headings. In some cases, differing perspectives prompted a refinement of the coding. However, the goal was not to achieve complete agreement, or to develop a joint coding framework: The researchers were interested in different aspects of the data, and approached the analysis from individual, similar but not identical, standpoints. During the analysis, they bore in mind the group context and any indications of participants' understanding of the purpose and aims of the research. From the outset there was an attempt to search for 'negative' examples, and put these alongside their relevant counterparts. The results of the provisional analysis were presented to, and discussed with, the wider group of authors.

Our interpretation is informed by the presence of two researchers in the groups and the joint approach to the analysis. While, unlike Agar and MacDonald (1995), we had limited access to additional ethnographic material, it would be simplistic to suggest that we made sense of the group interaction purely on its own terms. There were instances where comments from participants, inside and outside the groups, allowed us to consider the views in a wider context, which included some knowledge of local rivalries and hospital politics. The group methodology supported the production of agreement and disagreement, and participants' views were sometimes more strongly challenged than would have been the case had we conducted one-to-one interviews. While we heard some individualistic approaches to practice, there was also a tendency towards the resolution or putting aside of differences, perhaps in the interests of future working relationships. Nevertheless, we felt that individual voices and a range of perspectives came through in the groups. Participants did not simply present public accounts and did not adhere to a unitary specialist view.

Our approach to the data

Throughout this paper, quotes are used to illustrate the themes that we considered relevant to the main focus of our work. That is, they concern the construction of expertise, as reflected in participants' *claims* about the content of individual and specialty expertise. These claims were made in a number of different contexts, often as part of a process of justifying involvement in the development or provision of palliative care for people with heart failure. By the same token, assertions about the lack of knowledge and expertise were used to argue against involvement. In other cases, claims seemed designed to support the individual's right to be present in the group, and qualification to speak on the topic in hand. The participants were, in effect, engaged in the construction of hierarchies of knowledge, power and expertise within the medical division of labour. This was undertaken both on a general conceptual level and on a more localised basis, involving relationships between specific individuals. The participants' talk incorporated references to their understanding of palliative medicine and palliative care, either explicitly or by implication. Much of the discussion concerned the boundaries between these concepts and various ideas of 'everyday' medical and nursing practice. In particular, the debates revolved around the ways in which palliative care was, or was not, different from the medical care provided by participants.

In planning the research, we had taken note of Strong's view of the risks of framing the medical profession as a largely undifferentiated mass of 'like-minded' practitioners (Strong, 1979). The different specialties we involved can be considered in terms of their theoretical positions relative to the various, potentially overlapping, concepts shown in Fig. 1. This conceptual continuum draws on a broadly Foucauldian view of the shifting scope of medicine's surveillance activities (Foucault, 1976; Armstrong, 1983). The latter may encompass both the biological lesions of the individual body and the 'health-related' behaviours of

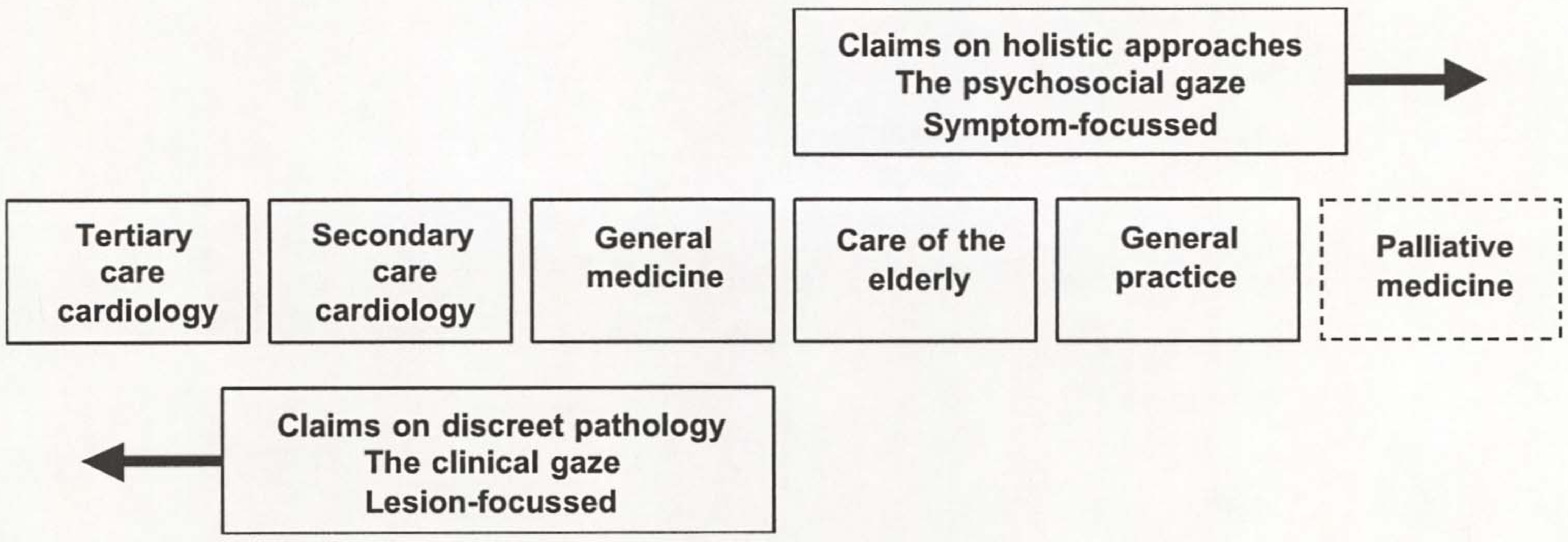

Fig. 1. A theoretical continuum of medical specialties involved in the care of people with heart failure.

the social body. On the continuum, hospital-based specialties are placed closer to 'technical' medicine than their colleagues in primary care, as in theory they have less opportunity to engage with patients in an everyday 'natural' psychosocial context. The apparent *precision*, according to the 'anatomical atlas', of the specialties' expertise has also been taken into account. Tertiary care cardiology therefore becomes the most focussed clinical expertise, given its concern with discrete pathology in a specific organ system and also because of the organisational locus of its practice. We have placed palliative medicine with due regard to its explicitly 'holistic' agenda. As with general practice, palliative medicine is theoretically more interested in the subjective experiences of patients than the 'objective' pathologies of the clinical gaze.

Findings

We emphasise at the outset that the focus of the discussions was the development of palliative care for a *new* patient group, as this has implications for the views presented. The groups often functioned as forums for establishing and challenging inter-professional boundaries, and renegotiating social order within the medical world. In the course of the discussions, specialist expertise and knowledge were framed and re-framed in support of individual and group positions. In presenting our findings, we consider firstly how participants presented the expertise of palliative medicine. To analyse this in more detail, we draw on the classification developed by Jamous and Pelloille (1970) of *technical* and *indeterminate* expertise.

Technical aspects of palliative medicine

We begin by examining the expertise constructed in the focus groups in terms of its technical, or readily codified, elements. In this context, and seemingly in line with our proposed continuum, participants presented palliative medicine in polarity with cardiology. The latter was used in the groups to represent a fundamentally 'clinical' medicine. The relevance of cardiology to palliative care was contested on a number of occasions, with some general practitioners citing a narrowness of focus and a reliance on technical interventions in support. Cardiologists were said to have a limited place, if any, in palliative care because they were not sufficiently 'holistic' in their outlook;

> General Practitioner Group 1
>
> AB1: I think a lot of district general hospital-based cardiologists are very frightened of patients with terminal heart failure because they can't do intervention. Basically you know most cardiologists in district hospitals are now interventive, which means that unless they are sticking tubes into the patient they really can't do their job...
>
> (Later in the group) BB2: I think in a terminal care situation then you probably need to keep the consultant cardiologist away from the patients (laughter) or they'll try and do too much. You know I've seen patients with terminal heart failure be resuscitated again and again and again, often against their wishes even...and that's a trick, to keep the consultant cardiologist away.

These 'stereotypical' views of expertise were sometimes used humorously, and suggest a level of shared understanding within the groups. Their expression might have been facilitated by the single-specialty group format, which served to emphasise participants' shared identity. The issue of status may also be relevant, with views of cardiologists perhaps serving to put these traditionally well-regarded specialists 'in their place'. Whatever the underlying intentions, they imply a degree of certainty about the position of cardiologists in the medical world that we did not find in the case of palliative medicine.

We can nevertheless identify some 'technical' aspects of palliative care expertise by considering its specialist strategies for the relief of symptoms. These comprise a contribution that the wider medical world regards as coherent, one that can be located straightforwardly within that world by other specialists. This expertise can be recognised as potentially superior to existing medical approaches, and even its more radical strategies can be assessed within a familiar clinical tradition of innovation, risk (re-)assessment and assimilation. A prime example is the case of opiate analgesia, which at first was used relatively liberally by palliative care specialists. Following what one of the palliative care participants described as 'a great battle', their approach to opiate use has been adopted within mainstream medicine. We saw another example of this recognition and privileging of palliative medical expertise in one of the groups. In the following extract, the first participant tells his colleagues about a new palliative care strategy for relieving breathlessness. He was using the example to illustrate the existence of a two-way learning process between his specialty and palliative medicine;

> Consultants in Care of the Elderly Group
>
> E: I, I think it's a joint thing. I mean one thing I have learnt about six months ago was that inhaled morphine is very good for breathlessness in heart failure, don't know if you've used this. You know it's very good, brilliant, absolutely brilliant.

> C: Nebulised or when, when you say inhaled how, how was that given?
>
> E: This is, this is er through a nebuliser
>
> C: Yeah a neb-
>
> E: you know a, you inject it in.
>
> C: Yeah
>
> E: And it's terrific, it, it gives a dramatic symptomatic relief and it was H (a Consultant in Palliative Medicine) who told me about this and I'd never heard of it before. I've heard of it in cancer, erm bronchial carcinoma, but never thought of in heart failure and it works fine.
>
> B: Inhaled morphine?
>
> E: Mm.
>
> C: Four hourly?
>
> E: No you, you just inhale it symptomatically, prn [when required], just take it when you're short of breath and it seems to last ages, you know several hours, six hours. Only had experience of ... two or three patients, you know it's not a series here (laughs).

While this technical expertise still requires negotiation with the wider discipline, its development in line with a recognisable medical epistemology means it can be fairly easily accommodated within a 'biomedical' or mechanistic approach to practice. Our analysis suggests that other components of palliative care expertise are less clearly delineated than this symptom-based contribution. It is these relatively *indeterminate* aspects of palliative care that form a significant challenge for the other specialties.

Indeterminate aspects of palliative care

Our change of emphasis here from palliative medicine to palliative care is deliberate, since these indeterminate aspects are often less firmly or consistently associated with palliative *medicine* as such. In the focus groups, indeterminate elements were often framed in terms of difference and challenge, and showed palliative care expertise at a point of maximal divergence from symptom-focussed medicine. The 'holistic' aspects of the palliative care agenda play a major role in this context. Thus, for example, palliative care was said to involve a 'different way of thinking' and a 're-orientation' of present services. Its rationale and underpinning philosophy provoked the requirement for 'struggle' against medical conditioning. The following participant argues that a palliative care specialist service is needed because it provides what clinical management, with its focus on adjusting medication, ignores. He makes explicit a connection between palliative care and the so-called biopsychosocial medical model (Engel, 1977):

> Cardiologists in Tertiary Care Group.
>
> C2: Well I mean I would say that the, that what I have observed is that there's a fundamental conflict between the disease-centred approach, which is the approach to treating the disease to improve symptoms, the treatment part of disease-centred approach, to a bio-psychosocial model of patient-centred care, which is what is intrinsic in palliative care programmes and palliative care approach...

This contrasting of palliative care with orthodox medicine promotes it as a *distinctive* expertise in terms of patient care. Part of the challenge of palliative care is in its focus on issues, notably death and the associated feelings of failure, which medical practice finds difficult to accommodate. The struggle that these issues represent for medicine can be seen in the following extract, where a cardiologist describes his involvement with a patient dying from heart failure. He used this example mainly to underline the difficulties of adhering to palliative care principles 'in practice'. A particular aspect he focussed on was honesty of communication, which he felt, at least up until the end, had been relatively open;

> Cardiologists in Secondary Care Group
>
> A4: ...it was still difficult to make a decision to go into terminal care mode. But it, it went reasonably well and at—I felt that I had a lot of input in the early stages, a lot of support of the heart failure nurse, but I still felt slightly uncomfortable as we went in to that terminal phase as to how am I dealing with this in terms of psychological and putting the news across to the patient—yeah I'm good at giving enough opiates and withdrawing unnecessary drugs, but I don't quite feel comfortable and I can't look her in the eye for long enough on the ward rounds because I'm not doing anything to save her life here...
>
> A5: You're saying as, in a way, albeit possibly subconsciously, you're feeling it as a failure?
>
> A4: Mm mm—'we've lost that one', but maybe, looking back on it now, we got it right, we didn't do bad—she kept going for many years longer than she might have done.
>
> (...)
>
> A5: and the palliative care physicians, you know fail well, as it were, or you know that's what the...
>
> A4: ... a good death is a success...

> A5: that's what they succeed, yeah, that's what they succeed at
>
> A4: yeah yeah
>
> A5: But it is a sort of psycho-, thinking psychologically, a different way and you know, the management of heart failure is lots of high tech, up to a point and it's difficult to switch from doing everything to feeling as though you're doing nothing.

The interpretation offered by another participant (*'You're feeling it as a failure?'*) suggests a shared understanding of the problem as a consequence of a medical emphasis on 'doing something': It forms an explicit and reflexive critique of 'heroic' medicine. This critique also operated in other groups, and was linked with an expressed desire to recalibrate public and professional expectations of medicine to a more realistic level. It is easy to imagine that, in such situations, the palliative care service might be regarded as a source of practical help and support for doctors as well as patients and carers. The referral to palliative care may constitute 'something to do' for patients regarded as being beyond the help of a medicine focussed on survival;

> Consultants in General Medicine Group
>
> G3: ...There was a patient stopped me on the ward—it wasn't my ward, I was visiting someone else—and he just said 'I've been told there's nothing else that can be done.' He's...he's a a chronic heart failure patient and he's basically just been told 'You go home and you you wait to die.' Really, and that's a tragic situation to be in, I think.

A potential difficulty here for the legitimacy of palliative care is that it becomes reliant on the other specialties' ability and willingness to categorise patients as being beyond help. We would emphasise again that the specific contribution of palliative *medicine* in the palliative care referral remains uncertain. To explore this further we will consider its negotiated boundaries with other forms of expertise, and particularly with 'medicine' as conceptualised by the group participants.

Palliative care: the boundary with medicine

Our examples so far illustrate the difficulty of locating the boundary between palliative medicine and the medical world, and that between palliative medicine and palliative care. Locating the expertise(s) of palliative medicine and palliative care is made more problematic if we describe also the 'generalist' (the palliative care physicians' term for doctors from all other specialties) participants' level of identification with such expertise. In addition to outlining personal participation in palliative care work, some participants in all of the groups formally distanced themselves from an objective and dispassionate medical science. They located medicine, at its purest and most technical, in departments of cardiology or casualty (which delivered 'maximum treatment') and medical textbooks. The following participants contrasted a tidy medical textbook view with a reality that included death as an outcome;

> Consultants in Care of the Elderly Group
>
> A: Well [heart failure]'s one of the first conditions that you're taught to diagnose and manage as a student isn't it?
>
> E: Mm.
>
> A: You know 'Is this person in pulmonary oedema?', 'Has this person got right-sided heart failure?' I mean it's all very common, and apparently very treatable.
>
> D: It is and if you actually look at sort of cardiology textbooks
>
> E: We understand the physiology of it
>
> A: Oh yes
>
> E: It's all fits together nicely doesn't it?
>
> D: Yeah it does.
>
> E: And makes a nice story.
>
> D: Now if you read cardiology textbooks and sort of look at prognosis and erm outcomes and that, very few of them mention death.
>
> E: Yes that's right, that's right.
>
> D: You know, you know death doesn't exist....

This sort of 'technical' medicine, while sometimes recognised as valuable or necessary, was nevertheless presented as being practiced elsewhere. The contrast between medicine in theory and practice was also made by some GPs, who felt that general beliefs about medicine's ability to 'cure' people were unhelpful, and did not reflect accurately the content of their daily work. One implication of the *negotiability* of participants' identification with 'clinical' medicine is that, if medicine claims to attend already to the 'biopsychosocial', the distinctiveness of the palliative care approach is compromised. The difficulty of identifying where regular care ended and palliative care began was often highlighted during the discussions. This was expressed in general terms and in the specific context of heart failure;

> Consultant in Care of the Elderly Group
>
> D: I mean palliative care to us er basically is not really new, because we, we do palliative care of sorts for all the time...

> General Practitioner Group 2
>
> A3: ...I mean after all you know the mortality of life is a hundred percent, everybody's dying, so you know what is, what is the difference between palliative care and good medical practice. That's really the, the way I see it anyway, so I mean you know obviously it incorporates good medical practice I mean but, what is the difference, why palliative care? You know there's text books 'palliative care', there's palliative care 'specialists', why palliative care, why not just an ordinary doctor?
>
> Cardiologists in Tertiary Care Group
>
> C1: ...much of what we do in cardiology is symptom management, although some people like to think that they're they're saving lives with certain treatments, a lot of a lot of everything that we do is symptom control...
>
> C3: Well, I think that the thing that perhaps it's important to stress, is that the treatment is used to achieve that is often much the same as the treatment that's used for people who are not terminal, which, in which case it contrasts rather with the management of, say malignant diseases, where terminal care and sort of therapeutic care are rather different.

Seale (2000) has previously noted the potential for underestimating the palliative care contribution of *existing* health care provision. As the above quotes demonstrate, this contribution was widely acknowledged in the groups, including by palliative care specialists. However, it is interesting in these claims that palliative care is still *tending* to be conceptualised in terms of symptom relief, rather than psychosocial or spiritual aspects (this latter dimension of palliative care was, in fact, rarely touched on the discussions). This supports our previous finding that within medicine, it is the symptom-focussed expertise of palliative care that is most readily understood. A further question about the perceived relevance of the 'holistic' and 'biopsychosocial' aspects of care to the *medical* world is raised by the role of nursing expertise in participants' accounts.

Palliative care and the role of the nurse

Participants often nominated nurses as the expert resource for accomplishing the work of palliative care. While nursing was not formally represented in the study, it is notable that two of the participants sought to recruit specialist nurse colleagues into the focus groups. Service development was seen to rely on there being more nurses, rather than more doctors. Nurses were said to have the 'time to give' for palliative care, and to have more time than doctors to sit and talk to patients. One palliative care physician felt that doctors did not 'like to perceive' time-consuming psychosocial issues as being within their remit.

The privileging of the nursing role in the 'palliative care' context was also often formulated in terms of particular skills and relationships with patients. Nurses were said to 'work better' with the patients, and to be better than doctors in terms of their 'commitment to individual patients'. Nurses 'knew' the patients and might therefore have a more accurate picture of what they thought. While the following extract describes a *joint* nurse/doctor approach to potentially difficult communication with patients, it also incorporates some of these assumptions about nurse–patient relations;

> Consultants in General Medicine Group
>
> G1: Often what I do as well is take a nurse from the ward along with me, who knows the patient, and I speak to the patient with the nurse involved, and you know, at least to introduce the subject and then ask her, would she mind, when she's got a quiet five minutes just see how much she's taken in and whether it needs reinforcing...I've found that quite useful, you know, take them a cup of tea and sit down and allow them to talk.

Nurses were seen as being able to provide support and education to patients and carers, 'making sure everybody understands'. One participant said they were better at approaching 'delicate things', and another felt they would enable an easier transfer of expertise between cardiology and palliative care than was possible with doctors. In terms of the relationship between nursing and medical work, views of nursing often promoted their distance from the technical medical agenda;

> General Practitioner Group 1
>
> DB4:...it maybe that there are some particular strengths in having a nursing approach to palliative care, because it's not an expectation they're going to cure somebody, and they're much more about caring and about communicating and about spending time rather than nipping in and out and saying 'Oh well just get on' and 'You're fine, we'll do this for you'. And so that may be a helpful philosophical adjustment for everyone concerned if it's led by a nurse who doesn't have this label attached above their head this invisible label saying 'I will cure you come to me and you will be healed'.

All of these views imply a degree of success for the nurses' professional rhetoric, by which their work is built increasingly on a relationship with patients constituted as subjects, rather than de-personalised 'objects' of care. May (1992) has previously given reasons why such work might not be successfully accomplished in practice. Not least of these is that the idea of individualised nursing care is in considerable tension with the organisational realties in which nurses actually practice.

One 'reality' of particular relevance in the present context is the way in which the nursing contribution to palliative care might be shaped in important ways by the professional dominance of medicine, as outlined by Freidson (1970). Thus, hospital-based nurses who visit patients in their homes and co-ordinate specialist services might appeal to hospital consultants partly as a means of extending their territorial control. In some groups, nurses were seen primarily as helping to sustain hospital-derived improvements once patients were discharged, for example by ensuring compliance with treatment regimes. They were also explicitly described as assisting cardiologists to express *their* expertise, which was reliant on a 'continuous amount of information', such as daily measurements of the patient's body weight. The emphasis of such a service therefore remains on symptom- and disease-focussed medical expertise. Medical dominance is reflected both in the idea that palliative care work may be 'safely' delegated to nurses (since this would not threaten the doctor's own sphere of expertise) and in the attempt to outline what is 'appropriate' in terms of the nurses' engagement with the 'psychosocial'.

Palliative care: compromising work for medicine

The association we have outlined between palliative care and nursing is consistent with a medical world in which technical expertise is prized and accorded high status. As we have perhaps already indicated, participants did not uncritically share this hegemonic view. The palliative care specialists sometimes seemed to downplay *deliberately* their 'scientific' or technical expertise: They described palliative care as being neither 'rocket science' nor 'glamorous' work, and the needs it addressed were 'down-to-earth'. This view of a 'basic/technical' polarity of need was also illustrated by one of the GPs;

> General Practitioner Group 2
>
> A1: you don't necessarily need to be able to get... thallium scans done tomorrow... but, but it would be really nice if you could get a proper care package set up for an elderly person so they weren't struggling round trying to look after themselves

An account of a consultation by one of the palliative care specialists seemed to invite, with some awareness, discreditable judgements about the nature of specialist palliative care work. She described her contribution in terms of 'just' listening to the patient, while he expressed his despair with his present circumstances. This led to some debate in the group about whether, as she had claimed, 'anyone' could have done this, and whether she might be underestimating the skill involved. While listening and sitting and talking might count as privileged activities in some settings, such as within the 'therapeutic gaze' of nursing work (May, 1995), their status as expert activities is contestable in the medical world. One of the GPs said it was unusual for him to accept the offer of a cup of tea in a patient's home. He might do this in exceptional circumstances, which he said could be taken to indicate a poor outlook for the patient. Later on in the group there was a further brief reference to the value of sitting and talking;

> General Practitioners Group 2
>
> A5: ...I suppose there isn't enough of the other stuff that goes on yeah.
>
> A3 The other stuff meaning, what, you mean sitting and talking to people?
>
> A5: Well... appropriately, yeah

To spend time on such activities may, therefore, be an 'inappropriate' use of medical expertise. As some of the examples in this section show, there is scope for a subversive view in which 'holistic' practice and open communication are valued more highly than technical, interventionist medicine. However, this serves to endorse the prevailing view of the low status accorded to practitioners of palliative care work.

The transferability of expertise

Further insights into the relationship between the expertise of palliative medicine and other medical specialties can be gained from the participants' views of 'learning from each other'. Whilst there was some acceptance that medicine could profit by exposure to palliative care thinking, some participants challenged the palliative care specialists on the grounds of their technical medical expertise. There was a view that palliative care specialists would have a limited contribution to make in 'heart failure', unless they also developed a competence in the clinical management of the condition. The palliative care specialists, who were mainly disinclined to seek legitimation in this way, were nevertheless aware of this as a contentious issue;

> Consultants in Palliative Care Medicine Group
>
> A3: The thing we actually have to learn, I mean we've learnt, that just even through in cancer, you know trying to get to nine different tumour specific groups, cancer has split itself up into, you know, the hundreds of groups, we are now expected to be knowledgeable and interface at all those, so specialist palliative care is being split five hundred ways just within the cancer diagnosis without actually trying to split yourself...

The palliative care specialists argued forcefully *against* an expansion of their present specialist services. Rather, a key principle of their strategy was educating 'generalists' to take palliative care principles on board. This is referred to in the following extract, in the context of the needs of people with heart failure;

> Consultants in Palliative Care Medicine Group
>
> A1: And I think, I think the number of people who have multiple complex needs is probably much smaller, I think what they have if we looked and - you see we don't know them as a group really - but I suspect that if we looked at their needs, if you addressed their bowels, their breathing and pain you'd probably cracked most of their problems
>
> A?: mm.
>
> A1:... so if you, if you share the knowledge that you have with the people who see them.
>
> A5: Bowels, breathing and pain.
>
> A1: Pain.
>
> A5: They can do it themselves.
>
> A1: You, they can do it themselves.
>
> A5: Hey presto (talking together).
>
> A?: There's nothing very mysterious

The emphasis placed on education by specialists in palliative medicine helps to answer the call for wider availability of palliative care in the context of limited resources. However, the suggestion that palliative care is part of the generalists' responsibility also seems counter to usual expectations of elitist professional groups. As explicitly recognised here, it is a 'subversive' tactic that deliberately puts professional mystique at risk.

Valuing specificity in medical expertise

We have described negotiations at the interface between palliative medicine and other specialties in terms of the potential threat they pose to the conceptual coherence and professional security of the former. Moves to promote equitable access to services, for example by people with heart failure, can be seen to compromise the well-defined focus of traditional palliative care on cancer patients at the end of their lives. The 'single mindedness and clear definition of problem' in the original hospice movement has been described as an integral part of its success (James & Field, 1992). The following palliative care specialist highlights the professional uncertainty about the present meaning of palliative care, and suggests a need to define specialist expertise more clearly;

> Consultants in Palliative Care Medicine Group
>
> A3: There are difficulties therefore about, um, I mean you said public perception and then it's health care professionals' perception, particularly I mean, I think primary health care can be very uncertain about when to refer to specialist palliative care and I think that's a lot of it is our fault because we've actually not defined it...we're used to defining the difference in palliative care and specialist palliative care but we're not very good at marketing that and making it very clear as to when we get involved. We're just starting that process and I think we do, but we inform the practice of palliative, general palliative care, I think it's our responsibility to drive standard setting and to inform the generalists of palliative care provision and that's perhaps something we don't do that well.

Baszanger (1990) has also noted the importance of standards, in which expertise is made visible, for the legitimation of professional activity. She described the case of a particularly disparate group of pain specialists in France that sought a 'place' in the medical world, but was hampered by the lack of consistent standards of practice. In the case of palliative medicine, its status and security are assured to some degree by its practitioners' medical qualification. This acts as a 'bridge of legitimacy' (Strauss, 1984), and confers immediate status and position on the newly developed specialty. The formal recognition of palliative medicine as a specialty by the Royal College of Physicians is a further indication of the legitimacy of its enterprise.

The belief in the importance of specificity of expertise evident in the groups can be linked to ideas about the appropriate and rational use of resources in the market of medical specialties. Furthermore, the debates about specificity and locating expertise did not only concern the relative newcomer of palliative care. They were also found, for example, in the tertiary care cardiologist group, where an orthodox view of cardiology expertise was repeatedly challenged within the group. One cardiologist summarised his colleagues' arguments against diversification, and for a clear and precise specialist service focus as follows;

> Cardiologists in Tertiary Care Group
>
> C2: ... It was even said in this room only two weeks ago, 'Do you really think this [palliative care] is something we should be getting involved in?' and I said 'It's something we, you know, morally and ethically are obliged to get involved in.' And I think that the general consensus was that it should be, but, you know, I think there are people that feel that we have a job to do, which is cardiac surgery, and bypasses and pacemakers and defibrillators and

> that's where, and that's our job, that's what we do - we're not Tesco's a supermarket chain, we don't sell everything, we just sell what we sell and it's up to somebody else to sell something else...

The indeterminacy of palliative care expertise poses some difficulty for other specialties in this regard. The ideal of a clear and precise definition of professional expertise can be seen in the frequent references in the discussions to the 'critical transition' (Ahmedzai, 1996). The need to identify the point at which the 'switch' to palliative care might occur for people with terminal heart failure became a focus of the debate in all groups;

> Consultants in Care of the Elderly Group
>
> A: And that's certainly where I'd see the biggest problem being the, the making, making that agreed decision both amongst the, the medical team but also erm with the patient and their family at, at what stage that switch is made. Because for most people, heart failure being such a very medical condition, the striving is always, you know on, on active therapy...
>
> Cardiologists in Tertiary Care Group
>
> C1: Quite where we cross the boundary towards disease management and trying to prevent disease progression, towards purely palliative or terminal care, to dealing entirely with the patient's symptoms is a sort of gradual process and it's difficult to just define when palliative care begins.

One of the roles formulated for medical science was the provision of reliable, precise and objective identification of this point in each patient's care, as underlined at the end of one of the groups:

> Consultants in General Medicine Group
>
> G4: I still feel defining that group is the crucial thing, so that we all agree that you know he's reached a stage where nothing can be done. And if you can predict the life span with some objective criteria, then we can sort of tell that to the patient, 'This is what it shows, if you come to this stage you're going to be living really for so long' and then it's easier to plan things accordingly...

While retaining a temporal boundary for palliative care expertise is helpful in terms of referral practices, participants often argued that the illness trajectory in heart failure did not allow a straightforward boundary to be set. The focus on a precise point where referral to specialist palliative care might be made underlines the separateness of palliative care from everyday medical practice. It therefore stands in contrast to the claims reported earlier, which emphasised the conceptual and practical overlap between them.

In terms of the boundary between palliative care and other forms of medicine, we have shown how the notion of distinctiveness of palliative care specialist expertise was both promoted and challenged in participants' accounts. In the final sections of the paper we will draw together some of the different strands to give an overview of palliative medicine's 'technical and indeterminate' expertise. We will also consider some implications of this analysis for the development of palliative care medicine beyond cancer care.

Discussion

Constructing the expertise of palliative medicine

We have outlined an important role for notions of 'expertise' in the focus group debates about palliative care for people with heart failure. The construction and negotiation of expertise concerned other specialties as well as palliative medicine. The view of expertise that emerges is an 'indirect' product of the participants' accounts, in that they were not formally asked to outline components of expertise. Specialty expertise was constructed from participants' personal motives and positions of sectional interest in debates about service development. The relationship between these shifting views of expertise and ideas of how services should be developed is complex. The contributions that we have outlined from the different specialties were not argued solely in terms of a rational division of labour, based on the theoretical content of their respective expertise. In the course of the discussions, roles and status were often assigned to specialties without an explicit or detailed rationale.

The picture from the focus groups is therefore more complex than our proposed continuum, might suggest. The boundaries between specialties in this context were dynamic and did not support a discreet placing of specialties. Furthermore, such a classification tends to under-represent what the participants have in common: They all share a medical identity and a medical apprenticeship, throughout which medicine's 'instrumental rationality' is a dominant force (Good, 1994). On the other hand, the continuum offers some insight into the relatively secure placing given by participants to cardiology. We have suggested that the success of this specialty in defining itself to its peers implies that expertise based on anatomical or disease criteria is regarded as particularly coherent in the medical world.

The continuum might also be useful in highlighting the moral work that underpins some of the views expressed about expertise. This becomes clear if we consider what the placements on the continuum suggest in terms of the medical orthodoxy. The latter is represented in Good's account (1994) of a clinical medicine that ignores the social and economic conditions that produce disease, and places low priority on, for example, helping patients achieve a good death. In his account, he also reports the response of some physicians to this view of medicine. They argued that, while his analysis might apply to physicians in tertiary care or medical students '*...as physicians mature, in particular in their primary care activities, attention to the lifeworld becomes more and more prominent as a dimension of medical practice.*' (p. 109). Critical views of the narrowness of the clinical gaze and claims to 'attend to the lifeworld' could both be discerned in our respondents' accounts. It is worth considering whether these might represent a 'distancing' strategy, in line with a widespread view of palliative care as more politically acceptable than other kinds of medical care. The generally positive image of palliative care, and increasingly critical public views of the medical profession might form the basis for 'rhetorical work' undertaken by participants. In this light, their accounts can be read as attempts to modulate the potentially negative assessments of others, including ourselves as researchers. (Billig, 1992; Radley & Billig, 1996). A specific imputation that doctors may be 'correcting' in these accounts of work and expertise is that of 'not caring'. It is important to acknowledge that claims made about expertise, and particularly identification with 'indeterminate' palliative care expertise, have a moral dimension.

In relation to this view of a medical orthodoxy, we have seen palliative medicine adopting a number of apparently subversive strategies that run counter to the expected means of claiming professional status and authority. One example is the palliative care specialists' apparently altruistic emphasis on sharing expertise, so that other doctors might become 'generalists' in palliative care. As the palliative care specialists themselves suggest, this reading might also be given to aspects of their work that involve spending time with patients and attending to the 'psychosocial'.

Implications for extending palliative medicine beyond cancer

We have outlined some of the wider policy issues that help explain why the negotiation of palliative medicine's role and expertise is particularly vigorous at this time. Various pressures on the service to broaden its scope and accessibility contribute to this being a critical period for the development of the specialty. It is therefore understandable that conceptual definitions continue to be the focus of tensions and difficulties. In our paper, we have not sought to clarify or solve the problem of overlapping definitions in palliative medicine and palliative care; rather we have highlighted some difficulties inherent in the attempt to make conceptual distinctions between 'specialist' and 'generalist' palliative care.

The diverse content of palliative medicine expertise and its emphasis on the psychosocial, are in some tension with the technical focus on symptoms and pathology (cancer). The amorphousness of this expertise may seem problematic, given the increasingly narrow specialisation of the medical market place. However, we should note that indeterminacy is broadly advantageous to the 'success' of a profession, since it facilitates rhetorical claims that are by definition difficult to substantiate. Jamous and Pelloille (1970) for example, consider medicine to be a profession with a relatively high 'indeterminacy' component. In the broader context of the profession, we can also see that palliative medicine has achieved notable success as a medical specialty. It has, for example, been endorsed by government policy (Department of Health 2000a, b), despite the absence of a convincing 'evidence-base' (Higginson, 1999; Salisbury, Bosanquet, Kite, Lorentzon, & Naysmith, 1999). In our groups, it is noteworthy that the palliative care doctors reported increasing workloads, and criticisms of the specialist service were generally about problems of access rather than its value. In a situation where the evidence of effectiveness privileged in medicine is absent, less 'objective' claims about expertise assume particular importance in the negotiation of roles.

We have indicated that palliative care expertise is most straightforwardly understood and accessed by the medical world in terms of its technical strategies for symptom relief. However, the promotion of 'technical' expertise has important implications for any moves to broaden the remit of specialist palliative medicine beyond cancer. While technical expertise confers credibility and status, it perhaps also serves to constrain involvement with the more challenging 'holistic' agenda. Palliative medicine has refined its technical expertise in the field of cancer care, and a move away from this is likely to weaken its claims for legitimacy in the medical world. As we observed, its authority and competence in managing the symptoms of heart failure were contested in the focus groups. Similarly palliative medicine is seen to operate within the temporal boundaries of 'end-of-life' care. This framework, too, would be challenged by the difficulties of estimating prognosis for patients with other diagnoses, such as heart failure.

The need to locate and define boundaries for palliative medicine expertise represents a search for coherence. The 'crisis of definitions' we describe has been precipitated by the attempt to consider new arenas and contributions for the specialty. The quest to re-clarify the location of palliative medicine in the medical world underlines the value of rationality for the social negotiation of medical expertise. However, the diverse conceptual bases of the specialties we have included in our study do not immediately suggest a clear organising rationality in the medical marketplace. While the value of coherence in practice remains uncertain, the participants in our groups refer to the ideal of the stable location of expertise in the medical world. Our analysis has detailed the specific ways in which the expertise of palliative medicine is constructed and used to clarify and stabilise boundaries with traditional medical and nursing practice. It indicates the scope of the negotiation that is needed for specialist palliative care to obtain a broader mandate to practice within the medical world.

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