Understanding end-of-life admissions: an interview study of patients admitted to a large English hospital shortly before death

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This dissertation is submitted for the degree of Doctor of Philosophy

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“So, you know, I’m not that familiar with people dying but it seems to me that most people don’t die like Old King Cole on the television, you know, with the family around looking sort of sad. They usually die from something that’s hurting or affecting them and makes them need specialist care. So I would think things like hospices and if necessary hospitals are probably where they ought to be but, you know, when I die I’ll let you know.”

(33,10)
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Declaration

This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text. It is not substantially the same as any that I have submitted, or, is being concurrently submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. I further state that no substantial part of my dissertation has already been submitted, or, is being concurrently submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. It does not exceed the prescribed word limit for the Degree Committee of the faculties of clinical medicine and veterinary medicine.
Abstract

Hospital admissions for patients close to the end of life are considered ‘inappropriate’ in contemporary English health policy. Hospitals are supposedly unable to offer a ‘good’ death for patients, and dying there is thought to contradict patient choice, since patients are assumed to want to die at home. However, almost half of all deaths in England in 2015 occurred in hospital, and of these, nearly a third died within three days of admission. This thesis seeks to explore why these admissions are considered to be a problem and how they occur.

Through a systematic review of UK literature I found that it cannot be stated that most patients want to die at home, because of the extent of missing data (preferences not asked, expressed, reported or absent). This finding challenges the justification that admissions are inappropriate because they contravene patient choice. Similarly inconclusive evidence about the undesirability, cost, and lack of need for patients to be in hospital were also found in a review of policy. Together with analysis of historical trends in hospital and hospice provision, it is apparent that attitudes towards end-of-life admissions reflect existing tensions about the role of hospital as an acute provider, and as a place of death.

An analysis of interviews conducted with healthcare staff and next-of-kin involved in the admission of patients (case-patients) who died shortly after being admitted to Meadowbridge, a large English hospital explored these tensions further. I found that whilst hospital was not recognised as a place where ‘good’ deaths typically occurred, it was acknowledged as an emergency place of care. In this context, patients without obvious need for hospital care were nevertheless admitted to the hospital and the environment was subsequently recognised to offer distinct benefits. The need for emergency care reflected the difficulties of providing end-of-life care in the community. For dying to occur appropriately, home had to be adapted and care organised by healthcare staff. Both tasks were complicated by the unpredictability of dying, and family carers helped to absorb much of the uncertainty and support patients to die at home. Ambulance staff became involved when patients had care needs that exceeded care quickly and easily available in the community. When called to the case-patients, ambulance staff instituted familiar practices in transferring them to hospital. Hospital was recognised as a default place of care because ambulance staff struggled to facilitate alternative care and lacked sufficient professional authority to keep patients at home.

The admissions of the case-patients represent the best attempts of staff to navigate the tangled practices of end-of-life care. These practices are the result of the actions of the staff, which in turn both constrained and enabled their action in providing care to patients. The term ‘inappropriate’ to describe admissions does not encompass these attempts, and moreover, devalued the significant care provided by healthcare staff in the community and hospital.
I am indebted to the support of my supervisors, Dr Stephen Barclay and Professor Mike Kelly, who have together guided me through this PhD process with great intellect and charity, sharing their time and extensive knowledge. Thank you to Stephen for creating such a conducive research environment -the generous praise and perceptive criticism, the support of my sociology aspirations, the funding (especially my 3rd year)- without which this PhD would have been much the poorer. Thank you to Mike for providing me with a map to navigate an unfamiliar sociological landscape, the reassurance to explore it, and for inspiring me to always strive to understand more.

The ACE study could not have occurred without the help of many people. Thank you to the healthcare staff and next-of-kin who shared their time and accounts of admissions with me. Thank you to the Meadowbridge Bereavement Office, who, in addition to facilitating access to patient notes and contacting next-of-kin, gave invaluable help and advice on the workings of Meadowbridge. Thank you to the Meadowbridge County Research Paramedic who performed the vital task of identifying ambulance participants and has continued to provide advice and information. Thank you to the Meadowbridge ACE Study Principal Investigator, who has supported the study long after it was intended to end, and who generously provided clinical insights into my conclusions. Finally, I am grateful to the Patient and Carer Group and the study Stakeholder Group, whose guidance was integral to the success of the study.

I owe much to Dr Zoë Morris, Dr Natalie Momen, and Dr Stephen Barclay for the ACE Study. Their collective work in conceiving, designing and organising the study provided me with a wonderful platform on which to explore end-of-life admissions, and I hope I have honoured their expectations of the study. I am especially grateful to Dr Zoë Morris for her guidance and support when I joined the Study. Dr Aileen Walsh taught me much whilst working together on the ACE study, and Sam Barclay provided invaluable help in anonymising the ACE dataset. Thank you to the systematic review team: Dr Zoë Morris, Dr Stephen Barclay, Isla Kuhn and Professor Mike Kelly, whose work I formally acknowledge in chapter 3.

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Preface

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Chapter one

“A sociologist contributes most when he [sic, repeated] reports what he has observed in such a fashion that his account rings true to insiders, but also in such a fashion that they themselves would not have written it. That is, most useful sociological accounts are precisely those which insiders recognize as sufficiently inside to be true but not so “inside” that they reveal what is already known.”([2]p.8-9)

“Although everybody has their own idea of what a ‘good death’ is, for most people it would involve being without pain, in a familiar place with close family or friends and being treated with respect. 75% of people say they would prefer to die at home. Recently, the number of people dying at home in has increased (42% in 2011), but over half of deaths still occur in hospitals.”[3]
Chapter 1

Hospital admissions at the end of life

1 Introduction

In this thesis I examine ‘inappropriate’ end-of-life hospital admissions in England. Hospital is the most prevalent place of death in England, and of those who die there, nearly a third (31%) die within three days of admission ([4]; below section 2.2). Reducing the proportion that die in hospital has been a key aim for end-of-life care policy, and as a consequence, end-of-life admissions are considered a significant problem [1, 5]. I explore why they are considered a problem and how they may occur. I do so by analysing interviews of healthcare staff and next-of-kin who were involved in an admission of a patient who died shortly after being admitted to Meadowbridge, a large English hospital. I also appraise the claims that contribute to the pejorative labelling of end-of-life admissions, including reviewing whether patients do wish to die at home, a central premise of early end-of-life care policy. In all these tasks I adopt a sociological perspective; accentuating the inherently social context in which end-of-life admissions occur in order to better understand them.

2 What are end-of-life admissions

2.1 The problem

End-of-life admissions became of significant policy interest with the publication of the Department of Health [1] end-of-life care strategy (EOLCS) in 2008. Whilst there had been concerns prior to this about the proportion of deaths which occurred in hospital, as well as negative interest in emergency admissions, the EOLCS was the first comprehensive framework for improving care for all patients throughout England [1], and thus its publication represented the introduction of a coherent attempt to address end-of-life admissions.

A key aim of the strategy was to increase the proportion of end-of-life patients able to die at home. Home was asserted to be where most patients and their families’ would prefer to be, in contrast to the apparent undesirability of hospital. These factors, together with concerns about the suitability of hospital as a site of death and the cost of hospital provision, made reducing hospital deaths a central focus of the EOLCS, and hospital
admissions a target [6]. So perceived, hospital admissions within the EOLCS and other policy documents are described as ‘unnecessary’ and ‘avoidable’, ‘inappropriate’ and as phenomena which can be ‘prevented’ and ‘reduced’ (e.g. [1, 7-9]).

2.2 Defining admissions

There is no accepted definition of ‘inappropriate’ end-of-life admissions [10]. Reviewing how they are described in the policy literature however makes it is clear that they broadly refer to admissions where it is perceived that patients could have received care in the community, had there been care available. Patients who do not have access to community care at all times (p.13), patients whose end-of-life status or preferences for place of care are not known (p.61), lack of well-coordinated care (p.84), care home patients transferred in the last week of life (p.90-91) were all associated with hospital admissions defined as problematic in the EOLCS [1]. Recent policy documents have additionally attributed such admissions to insufficient discussions with the patient about their end-of-life preferences, on the presumption that if it had been known patients wanted to die at home, their care could have been so organised (p. 25-26 [5]). By contrast, hospital deaths considered to be unexpected are exempt from descriptions of ‘inappropriate’ admissions¹ (see Appendix 1 for endnotes). The EOLCS also establishes an interest in reducing length of stay in hospital ([1]p.16). Together these factors imply that patients who are known to be end-of-life and who are admitted shortly before death are the epitome of ‘inappropriate’ admissions. It is presumed that these patients do not need hospital care, and could have been more appropriately cared for to their death at home.²

This concern with admissions where patients die shortly after being admitted corresponds with their occurrence. Patients who die in hospital within three days of admission count for almost a third (31%) of hospital deaths and nearly a sixth (14%) of all deaths in England³ [12].

3 Why study admissions

That nearly a sixth of all deaths occur in hospital shortly after admission challenges the contention that end-of-life admissions must be ‘unnecessary’ and ‘inappropriate’. Despite this, they remain an important focus for end-of-life care with the percentage of deaths in hospital⁴ a key metric for end-of-life care quality, whereby decreasing proportions of hospital deaths indicates increasing success [5]. End-of-life admissions therefore presents an intriguing sociological riddle; how something that occurs routinely has been
Chapter 1

construed as problematic, and given the condemnation, how it persists in occurring. Moreover, regardless of whether admissions are, or are not, problematic, their prevalence means understanding how they occur will provide useful insight into end-of-life care generally.

There has been limited published research that engages with the negative portrayal of end-of-life admissions, perhaps because of the persistence of the rhetoric about the importance of place since the publication of the EOLCS (with notable exceptions, including [6, 10, 13-16]). The lack of questioning about the way hospital admissions are conceived – their ‘inappropriateness’ - may affect the way staff and family view hospital care, and limits the understanding we have of these admissions. If end-of-life care is thought to best occur at home, and appropriate planning the best way to achieve this, it is inevitable that hospital admissions will be pejoratively described. In this context, hospital can seldom fulfil patient choice and must necessarily be a failure of appropriate planning. As a consequence of the placement of hospital as antithetical to home, hospital care following an ‘inappropriate’ admission is necessarily inadequate, just as the admission itself is the fault or ‘problem’ of someone involved. Furthermore, by framing admissions as a violation of good end-of-life practice, as ‘preventable’ and ‘avoidable’, conventional understanding about why they occur is focused on ways in which best practice is not achieved.

By comparison, if admissions are portrayed not as an anomaly but are instead recognised as a part of contemporary end-of-life care (which their prevalence suggests they are), there is greater scope to understand them because it is now possible to draw on a wider range of potential reasons for their occurrence. From here, best practice itself can be scrutinised, and for instance, the feasibility of planning death [17], or of prospectively organising end-of-life care, can be assessed alongside established understandings about why admissions occur, such as inadequate planning [6].

4 How to study admissions

4.1 Sociologically

In this thesis I seek to understand how and why end-of-life admissions occur by considering them outside of the constraints of the current binary distinctions offered in contemporary discourse of ‘appropriate’ and ‘inappropriate.’ I do so by using a sociological lens. Exploring these admissions sociologically seems pertinent not only because of my training, but also because the issues that lead to patients being admitted
appear to me to originate as much from the social patterning of healthcare organisation, as from the patients’ specific medical need for admission.

This sociological lens provides a different insight to the many reviews and reports that have been published since the EOLCS [18]. The novelty of a sociological exploration is the potential to bring to the fore the social practices which constitute admissions, helping to explore the occasions when putative best practice did not occur, as well as to consider the notion of best practice itself. This approach necessarily complicates our understanding of end-of-life admissions by embracing the complexity of the processes involved [19] but it also illuminates them in ways that have not been considered by policy makers and practitioners hitherto. It also allows for end-of-life hospital admissions to be recognised as neither desirable nor undesirable in themselves, but as emergent properties of the network of social practices which make up the admissions system. Importantly, it permits admissions to be considered in a non-judgemental way and therefore to move the focus from culpability to a recognition of the complicated social environment in which admissions occur.

Though I suggest in the conclusion possible ways in which end-of-life care, including hospital admissions, could be improved it is beyond the scope of this thesis to provide solutions to end-of-life admissions, and my aim instead is to contribute to the scholarship on end-of-life care. From this collective solutions, if deemed appropriate, may be developed. My approach of not deeming admissions to be necessarily inappropriate offers potentially more achievable suggestions, such as improvements to hospital care for dying patients, rather than the formidable task of trying to prevent admissions from occurring in the first place.

Whilst my exploratory tools will be sociological, with a particular interest in the interplay between structure and agency, I intend for my research to be grounded in the practice of end-of-life admissions. As such, I deal with substantive sociological theory in the discussion (chapter 8). There I use sociological ideas to pull together my empirical findings and develop richer insights into these admissions than could be achieved without this body of work. Through doing so, I have striven to achieve Glaser and Strauss’ ‘useful sociological account’ quoted at the start of this chapter.
Chapter 1

The ACE Study

In order to understand how and why admissions occur, I have analysed interviews of healthcare staff and next-of-kin involved in the admission of end-of-life patients. These interviews derive from the hospital admissions close to the end of life (ACE) study, which took place at Meadowbridge, a large hospital in England. The study, designed by my supervisor Dr Barclay and others, took a novel approach to researching end-of-life admissions by designing a retrospective study [20]. Focusing on nine patients who died within three days of admission, the study reconstructed the patients’ admissions by talking to healthcare staff and next-of-kin who had been involved in its occurrence, from both community and hospital settings. As a research assistant, I conducted the interviews between 2012 and 2013 (prior to starting my PhD), and was involved in shaping the design and conduct of the study. In this thesis I analyse these interviews to understand the social environment within which these admissions occurred; the structures which enabled and limited healthcare action, the agency of patients, carers and staff, and the materials, knowledge, meanings and practices necessary for these admissions to occur.

4.2 Definitions

In this thesis I use the terms ‘end-of-life care’ and ‘palliative care’ interchangeably for simplicity. Whilst these are discrete terms, they are often used synonymously, including by participants in the interview study [21]. I will use either term to refer to care provided to patients with advanced disease that aims to manage pain and “other problems, physical, psychosocial and spiritual” [22, 23]. I will use the term ‘end of life’ in line with the General Medical Council [22] to refer to the last 12 months of life. End-of-life patients therefore will be those considered to be “likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events”([22]p.86-87).
Boundaries

My interest is in the process of the admissions, rather than the death in hospital. Reflecting my lack of medical knowledge and wish to focus on the concept of admissions, I do not make judgements on whether patients should have been admitted to hospital, nor on the care patients received once in hospital. Likewise, I do not review the care (medical or nursing) patients received prior to their admission to hospital, beyond the most obvious generalities. My main focus is on the patients’ transfer to Meadowbridge, and prior to this their experiences at home. Whilst alternative places of care such as hospice and care home are significant in English end-of-life care provision and thus to understanding admissions, they were relatively absent in the accounts I explored of the case-patients. Similarly, my focus is solely on patients who were admitted and died in Meadowbridge. This could be construed as a focus only on admissions where end-of-life care has ‘failed’. However, this explanation requires subscribing to the idea that a hospital death must necessarily be a poor outcome, a contention I challenge throughout this thesis.

4.3 Research objectives and questions

The aim of this research is to understand ‘inappropriate’ end-of-life admissions. To achieve this, I have two research objectives:

1) To assess the context of end-of-life admissions through a) a review of patient preferences for place of death, and b) an examination of the historical precedents to the definition of some hospital admissions as ‘inappropriate’

2) To explore qualitatively, through the analysis of healthcare staff and patient interviews, how and why some end-of-life admissions occur.

My research questions are therefore:

1) Do patients prefer to die at home?

2) What contributes to the ideas that hospital is a bad place to die, and end-of-life admissions are a problem?

3) What are the views of healthcare staff, patients and families about end-of-life admissions?

4) What are the dynamics of the processes leading to end-of-life admissions in the community?

5) What are the dynamics of the processes leading to ambulance staff facilitating end-of-life admissions?
Chapter 1

5 Overview of the thesis

Following this introductory chapter, I begin by assessing in chapter 2 the idea that most patients would prefer to die at home through a systematic review of patient preferences in the UK, finding contentious evidence in the form of significant missing data. Since this challenges a key justification for reducing hospital admissions, I explore in chapter 3 the social, political and historical context of hospital admissions. From this research it is evident that an ‘inappropriate’ hospital admission is a fluid concept that has roots in the development of the hospital and bureaucracy and reflects wider political concerns than just end-of-life care. It is apparent that there is much research on how admissions occur, how to prevent them and what they mean, but little on why they occur. In order to address this, I outline in chapter 4 a methodology for conducting an analysis of the ACE study, including reviewing the context of the analysed interviews. In chapter 5-7 I explore the findings of this research, considering in turn the role of the hospital, community and ambulance service. After undertaking this analysis it was apparent that the admission of patients may be construed as a profoundly sociological problem whereby healthcare staff, patients and family carers are restricted in their ability to provide care as they would wish by their social surroundings. In chapter 8 I consider this problem, drawing together issues highlighted in the preceding chapters with relevant sociological literature in order to gain a more comprehensive understanding of hospital admissions. I conclude in chapter 9 with a brief overview of my research, and how it may usefully contribute to end-of-life care, and sociological research.
Chapter two

“whether we can shift hospital death safely into community, because that’s clearly what surveys tell us that people think they want, although if that’s what people actually want in their final hours is a different matter”

(31,4)
Substantive work from this chapter has been published as:

Hoare, S., Morris, ZS., Kelly, MP., Kuhn, I. and Barclay, S. (2015), 'Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death', PLoS ONE, 10 (11), e0142723.

The chapter is the result of collaborative work between the publication authors; myself (SH), former ACE Study researcher Dr Morris (ZM), medical librarian Ms Kuhn (IK) and my supervisors Dr Barclay (SB) and Professor Kelly (MK). Where authors undertook specific tasks in the research of this chapter, this has been made explicit within the text. Specifically (and in order of contribution), the study was conceived by ZM, SB, designed by ZM, SB, SH, with data analysed by SH, ZM, MK, SB, and the revised research strategy developed and electronic database searches completed by IK. SH led on the analysis, wrote the first draft of the published paper, and subsequent revisions following discussion with the other authors. SH led the submission process and all the dealings with the editor of the journal. The following chapter is an updated version of the published paper.
Chapter 2
Reviewing preferences for home death

The ‘problem’ of end-of-life admissions is tied to the policy focus on patient preference for place of death, which is assumed for most to be a preference for home. Enabling patients to achieve this wish has remained a central aim of UK end-of-life care policy since the publication of the EOLCS, with place of death persistently used as a key performance indicator for quality⁶. In order to understand the ‘problem’ of hospital admissions then, it is pertinent to begin by exploring the assertion that most people prefer to die at home.

In this chapter I report a systematic review of the UK literature of preferences for place of death at home and other locations, examining the extent of unreported preferences, the importance of patient factors (place of care and health diagnosis), and the role of the preference-giver. I begin by outlining relevant issues about place of death, considering the nature of, and potential differences between, general public and patient preferences. I consider next the review approach I took, before describing the results of the review and the overall finding that it is unknown what proportion of UK patients prefers to die at home. I conclude by assessing the importance of this result for understanding end-of-life admissions.

I Do dying patients want to die at home?

Surveys of the general public routinely find a majority preference for home as a place of death, with commonly reported proportions of between 56-74% (e.g. [8, 24, 25]). However, academics and palliative care specialists are increasingly questioning whether the views of the general public accord well with those of dying patients (see for instance [26, 27]). Patient preferences are typically sought to inform future care and therefore can be expected to hold a different significance to those asked as part of a general survey ([28]; chapter 3 section 1.2.2). Furthermore, whilst both respondent groups are asked to give an answer to an event they have not experienced for themselves, the imminence of death for dying patients, in addition to their recent experiences of care, will provide relevant contextual information which general public respondents are unlikely to be able to draw upon [27].
Chapter 2

There are also problems with what is not reported in study findings. It is unknown how those who were unwilling to express a preference are treated in research about place of care and place of death [29]. This is a problem because respondents are typically restricted to choices between home, hospice, care home or hospital, whether the questions are asked of the general public [30] or dying patients [31]. Moreover, preferences for place of death given by terminally ill patients are recognised not to be categorical choices. Instead they have been found to be highly contingent and dependent on the support available [32], often ill-defined and evolve as the patients’ health deteriorates and their needs change [33]. For all respondents, these four choices may not be representative of where they wish to die because they would prefer to die elsewhere; studies which provide more options report for example preferences for ‘prison’ and ‘caravan’[34]. If either possible participants, or discrepant views are excluded, it has the potential to significantly misrepresent patient views and hide the nuances of the preferred place of death decision-making process, in turn challenging the rhetoric about the ‘inappropriateness’ of hospital admissions.

2 Reviewing patient preferences

To assess patient preferences for place of death it is useful to explore the available literature. A systematic literature review provides a useful method to assess the available evidence. It is a method well suited to assessing ‘spurious certainty’ because of its ability to consider a large body of literature and for its explicit aim to limit bias [35]. It is also suitable for assessing quantitative data, important given that these data are the basis for the evidence on preference for place of death [28].

In this review we considered specifically the role of “missing preferences”- participants excluded from analysis since their preference was not asked, expressed or reported. Preferences were examined in three ways: whether the participant had a malignant diagnosis, whose preference was reported, and where participants were asked their preference. We focused on disease because end-of-life care policy provision has historically considered the needs of cancer patients [1], and therefore it is plausible that patients with other conditions may have different preferences which are not as well recognised. We considered the role of a participant because how preferences are considered may be different for a dying patient compared to a family member acting as a proxy for a dying or deceased patient or a member of the public [27]. We considered the place of an end-of-life participant’s care because patients experiences of care settings have been shown to be a contextualising factor in where they choose to die [32]. As place
of care is not always documented, we used the proxy measure of where participants were asked their preference.

The review questions were therefore:

- Are there differences in the preferences for dying at home in cancer patients compared to patients with other conditions?
- Are there differences in the preferences for dying at home as reported by patients, family members, health care professionals or the general public?
- Are there differences in the preferences for dying at home by where participants are asked their preference?
- What is the extent of missing data on these reported preferences?

2.1 Review history

The literature review had a protracted history as shown in Table 1, which also documents those involved in each task. Between 2012 and 2014 the review criteria were established by ZM, and together we conducted an initial review to establish search terms, followed by a review of academic and grey literature and a hand search of a journal, and a subsequent updating of this initial review. The results of these tasks are hereafter referred to as the ‘scoping review’. The scoping review search strategy can be found in Appendix 2, and the results of it were reviewed using the inclusion and exclusion criteria outlined below (section 2.2).

In 2015, it was apparent that the search strategy of the scoping review was not appropriately robust and it was revised and improved by IK in consultation with me (see Box 1 for updated strategy). IK conducted a database search for papers published between 2000 and January 2015 in the following databases: Medline, Embase, PsycINFO (all via OVID), CINAHL (via EbscoHOST), Web of Science, Scopus and ASSIA (via Proquest). I also conducted a hand search of the journal Palliative Medicine (the most prevalent journal for included articles), a grey literature search (Box 1) which had formed part of the scoping review, and a citation search of all included papers for other peer-reviewed papers. Together with papers already known to the authors’, this completed the search strategy.
2.2 Inclusion and exclusion criteria

We included articles if they were: published between 2000-2015, written in English, conducted in a UK setting, and reported quantifiable, empirical data on adults’ preferences for place of death. The date criteria was used so as to build on Higginson and Sen-Gupta’s [36] 2000 literature review. Since others have reported few high quality papers on preferences for place of death since 2000 [28], we applied a quality measure and included the ‘grey literature’[37]. We restricted the literature to UK populations to increase the homogeneity of health service and cultural context. Likewise, we focused on adult preferences only, reflecting the differentiation at the time between adult and child end-of-life care [1]. It was necessary to include only quantifiable data, given the data analysis we wished to complete. Opinion pieces, conference abstracts and news reports were excluded unless they contained original empirical data.

Table 1  Timeline of review development

<table>
<thead>
<tr>
<th>Year</th>
<th>Tasks (in chronological order)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scoping review</strong></td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>Review search terms in existing literature ZM</td>
</tr>
<tr>
<td></td>
<td>Conducted review of literature to assess search terms SH</td>
</tr>
<tr>
<td></td>
<td>Results reviewed by ZM, SH</td>
</tr>
<tr>
<td></td>
<td>Conducted search of academic literature SH</td>
</tr>
<tr>
<td></td>
<td>Articles reviewed SH, ZM</td>
</tr>
<tr>
<td></td>
<td>Added data into table, calculated missing percentages SH, ZM</td>
</tr>
<tr>
<td>2013</td>
<td>Hand search of palliative medicine SH</td>
</tr>
<tr>
<td></td>
<td>Conducted grey literature search SH</td>
</tr>
<tr>
<td></td>
<td>Reviewed and weighted all included data SH, ZM</td>
</tr>
<tr>
<td></td>
<td>Added new data into table, calculated missing SH, ZM</td>
</tr>
<tr>
<td></td>
<td>Drafted first paper ZM</td>
</tr>
<tr>
<td></td>
<td>(SH started PhD)</td>
</tr>
<tr>
<td>2014</td>
<td>Updated literature search SH</td>
</tr>
<tr>
<td></td>
<td>Updated search of palliative medicine SH</td>
</tr>
<tr>
<td></td>
<td>Updated grey literature search SH</td>
</tr>
<tr>
<td></td>
<td>Reviewed, weighted all included data SH, SB</td>
</tr>
<tr>
<td></td>
<td>Added new data into table, calculated missing SH</td>
</tr>
<tr>
<td></td>
<td>Constructed graphs of data SH (analysis support, SB, MK)</td>
</tr>
<tr>
<td></td>
<td>Completed draft of paper SH</td>
</tr>
<tr>
<td><strong>Systematic review</strong></td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>Revised search strategy IK, SH</td>
</tr>
<tr>
<td></td>
<td>Conducted database search IK</td>
</tr>
<tr>
<td></td>
<td>Reviewed, weighted all included data SH, SB</td>
</tr>
<tr>
<td></td>
<td>Backwards citation search SH</td>
</tr>
<tr>
<td></td>
<td>Wrote paper draft SH</td>
</tr>
<tr>
<td></td>
<td>Revised draft SH, IK, SB, MK</td>
</tr>
<tr>
<td></td>
<td>Paper submitted to journals SH</td>
</tr>
<tr>
<td></td>
<td>Paper amended following reviews SH (support by MK, SB)</td>
</tr>
</tbody>
</table>

Shaded cells = work SH led on
Chapter 2

Box 1 Search terms for peer-reviewed and grey literature

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
<th>Search terms</th>
<th>Total</th>
<th>Read</th>
<th>Included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cochrane</td>
<td>19/03/14</td>
<td>Place care</td>
<td>271</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>&quot;</td>
<td></td>
<td>Place death</td>
<td>107</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>&quot;</td>
<td></td>
<td>preference place of death</td>
<td>7</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Grey literature</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NICE</td>
<td>20/03/14</td>
<td>Pref* place care</td>
<td>484</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Dying matters</td>
<td>20/03/14</td>
<td>Pref* place care</td>
<td>24</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>Social care online</td>
<td>25/03/14</td>
<td>(pref* and care) or (pref* and death)</td>
<td>1404</td>
<td>123</td>
<td>3</td>
</tr>
<tr>
<td>NHS Evidence</td>
<td>20/03/14</td>
<td>Pref* place care</td>
<td>3533</td>
<td>134</td>
<td>2</td>
</tr>
<tr>
<td>19/03/14</td>
<td>End of life care</td>
<td>14</td>
<td>4</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>King's fund</td>
<td>25/03/14</td>
<td>Pref* place care</td>
<td>25</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>&quot;</td>
<td>Place death</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>&quot;</td>
<td>preference</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Nuffield Trust</td>
<td>19/03/14</td>
<td>Searched all publications post 1999</td>
<td>216</td>
<td>24</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6275</td>
<td>465</td>
<td>8</td>
</tr>
</tbody>
</table>

Grey Literature search strategy and terms varied to accommodate the available number of documents on each website and search engines provided. It was thus possible to screen all the relatively small dataset of Nuffield Trust publications since 1999: a more targeted search was conducted of the approximately 150,000 records in the Social Care Online database.

Amended from Figure 1 by © Hoare et al. 2015 licensed under the terms of the Creative Commons Attribution License

2.3 Selection and evaluation of studies

The search results were downloaded into the reference programme EndNote and duplicates removed. I screened potential titles to remove irrelevant papers and then reviewed the included abstracts with either ZM or SB. I then obtained the full text of potential papers, and reviewed these with the same review team. Figure 1 provides a flowchart of the literature search.
The same team then independently weighted each included paper for its contribution towards answering the review questions using Gough’s Weight of Evidence (WoE) Framework [37]. Across the review, differences were reconciled through discussion. Details of the Framework and the weighting method are shown in Figure 2. I conducted a sensitivity analysis of included papers to investigate the impact of removing the lowest weighted papers but found no meaningful change in results; and therefore we included all papers.
2.4 Data Synthesis

I extracted data from each included paper and tabulated the information in Microsoft Excel, with amendments and checking conducted by ZM in the scoping review, and by me in the full review. I constructed separate spreadsheets which categorised studies by: main diagnosis of participants (cancer, non-cancer, multiple conditions, not stated and ‘public’ to refer to participants surveyed as a member of the general public); who reported the preference (patients, family or other informal carer, healthcare professionals and public) and setting (care home, home, hospice, hospital, multiple settings or ‘not applicable’ as participants were not patients or reporting on behalf of patients). To explore the impact of ‘missing data,’ I then calculated the proportion of ‘missing’ preferences (participants whose preferences were either not recorded in the study or not reported in the paper) and reproduced the spreadsheets using the amended preference proportions. The ‘missing’ preferences were included as a discrete category since they could not accurately be included in any of the other pre-existing preference categories. Both sets of spreadsheets were plotted as bar charts with lines superimposed indicating median, maximum and minimum home preferences for each category (see Figure 3, 4, 5).
Chapter 2

2.5 Reporting data

If several different samples were reported in the papers, I included only that most relevant to the review. Where possible this was the ‘total’ preference for place of death of the entire sample but where this was not reported I calculated it from the available data, where feasible. Where this was neither possible nor appropriate, for example where data were reported from different years, I reported both populations. I merged preferences for ‘don’t mind’ and ‘no preference’. Likewise, where participants were not decided or were reported to have a preference of ‘changed mind,’ I categorised this as ‘Unsure/it depends.’ I categorised reported non-responses as ‘missing’ unless a reason was given which meant that the response could be otherwise categorised (e.g. reported as ‘undecided’). I categorised references to nursing or residential home as ‘care home.’

The included review studies were diverse in terms of: populations and settings; sampling methods and sample sizes; and research methods. To test the data implications of this I stratified the sample by data source and found no evidence of systematic confounding (see Appendix 3). The considerable heterogeneity in the sample meant I was not able to undertake a meta-analysis to provide an overall percentage for home death preference, nor to test statistically the relationships between categories and preferences for place of death. As the data were not normally distributed, I provide medians rather than means.

3 Results

3.1 Overview of the study data

The scoping strategy yielded 1,973 titles, the full strategy 8,853 titles and I combined the results together with those from the grey literature search and additional searches. In total, 61 reports met the review inclusion criteria. Three reported duplicate data ([38, 39]; [40, 41]; [42, 43]) and I combined these in the analysis leaving 58 discrete papers. Several studies reported datasets of multiple populations; three contained two datasets and therefore I included these twice [44-46] and two studies generated three reports [47],[48] and are therefore represented three times each. This brought the total number of included reports to 65.

I weighted five reports as “high” using Gough’s ‘Weight of Evidence’ Framework [29, 32, 34, 49, 50]; 38 reports were weighted as “medium”, often due to their focus on the general public rather than participants close to the end the life. The remaining 15 reports were given a “low” weight. These included conference poster abstracts, letters to journals, grey literature reports of projects not designed to be of high academic standard,
and studies where, for example, samples were not described or participant preference data were limited to home preferences alone. Appendix 4 summarises each the included reports.

The fifty-eight included studies were research papers (n=34), poster abstracts (n=8), reports (n=9) (including 4 NHS reports), letters to Editors (n=5), a conference abstract (n=1) and a website report (n=1). There was large variation in studies’ aims. Some were concerned with measurement of concordance between preferred and actual place of death, others the evaluation of service redesign on place of death, still others were audits of current preferences to inform service redesign or population studies seeking to inform EOLC policy.

The included papers had diverse research methods. Patient records (n=32) were commonly consulted often from Preferred Priorities for Care documents (n=11) (an advance care planning tool designed to encourage the discussion, recording and implementation of patient preferences). Others used questionnaires and surveys (n=19), interviews (n=5) or a combination of these methods (n=2).

Most of the reports (n=21) included a range of cancer and non-cancer illnesses. Some (n=12) did not state the participants’ illnesses, some studied only cancer (n=8) or specific non-cancer conditions (n=7) [51-55]. None of the studies of the general population (n=10) had a specific disease focus, except for one which asked respondents to respond as if “in a situation of serious illness like cancer”([40]p.7).

The majority of reports were of patient preferences (referred from here on as ‘participants’) (n=48), of which a minority were proxy reports from family carers (n=11) or from healthcare professionals (n=1). Ten of the reports were surveys of the general population (referred to from here on as ‘public’).

The included reports use data collected in a variety of settings; hospital (n=10), hospices (n=8), participants’ homes (n=5), care homes (n=2) and in the ‘community’ (GP surgeries or a variety of non-acute settings) (n=6). Studies were also undertaken in ‘multiple’ settings where participants were asked in either primary and secondary care or where the participant was responding on behalf of a patient (n=17), or among the general population where location was not relevant (chart category ‘N/A’ (n=10)).
3.2 Preferences for place of death by participant condition

Figure 3(A) displays preferences for place of death by participants’ main condition. Across all conditions (and none), median preference for home varied only by 9 percentage points, suggesting a broad consensus across all conditions and the public. However, the range of public preferences was much smaller than the range for all other categories (19 percentage points for the former compared to ranges of between 54 (cancer participants) to 100 (disease focus not stated)).

When missing data were included (Figure 3(B)) the consensus between participants and the general public disappeared. Only in studies of the general public did median preference for home exceed 50% (median = 62%). Median preference for home for all participants fell; amongst cancer participants to 36%, for multiple conditions to 28%, non-cancer to 42% and for those where the disease focus was not stated to 35%.

3.3 Preferences for place of death by participant role

When considering the roles of contributors, preferences of participants and the general public were broadly similar (Figure 4(A)), with median home preferences of 60% and 63% respectively. However, the range of responses for home was much larger among patients than the public (85 versus 19 percentage points respectively). Studies of patient preferences collected by asking proxies, usually family caregivers (often after the patient’s death), had a high median preference for home of 72%, exceeded only by the one study of healthcare professional proxy perspectives of patient preferences (median 100%). In all but one of the studies of family caregivers, home was the preferred place of death of at least 58% of respondents; the exception was a study where all respondents chose care home [56].

Figure 4(B) shows preferences by participant role with missing data included. Home preference reported by patients and family members were markedly reduced (to 40% and 27% respectively). Of the 12 studies of family preferences, 9 had large amounts of missing data, ranging from 33-72% of all responses. The single study of professional perspectives [57] had no missing data. Patient preferences for home death had a very wide range of 82 percentage points. Public preferences had little reported missing data and median home preference remained high at 62%.
Figure 3 Preferred place of death by patient condition (A) and preferred place of death by patient condition including missing data (B)

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Figure 4 Preferred place of death by participant role (A) and preferred place of death by participant role including missing data (B)

Figure 5 by © Hoare et al. 2015 licensed under the terms of the Creative Commons Attribution License
3.4 Preferences for place of death by where participants were asked

Figure 5(A) shows the respondents’ preferences according to the setting in which they were asked. In the two studies where participants were care home residents, all chose care home as their preferred place of death. Participants at home or in the community tended to prefer death at home (median 81% and 78% respectively). In all but one of the five ‘home’ studies at least 79% of participants chose home [49]. Participants in hospice had lower preferences for home (median 60%) with hospice as the second largest or majority preference in 11 of 12 studies. Those in hospital had the lowest home preferences of all locations (median 50%), excluding care home participants. Participants asked in multiple settings gave home as the most frequent preferred place of death in all but one study (median 68%). In all general public studies (setting ‘n/a’) home was the preferred place of death for at least 55% of each study (median 63%).

When missing data were included (Figure 5(B)), median preference for home was greater than 50% in participants in the community, at home or members of the public; for all other groups the median preference for home did not exceed 33%. At least half of studies in hospice, hospital or multiple locations recorded more than 33% of missing data (6/12, 6/11 and 12/18 respectively, where number of missing studies/total number of studies in category). Median preferences for care home remained high amongst studies of care home participants (92%).
Figure 5 Preferred place of death by where participants were asked (A) and preferred place of death by where participants were asked including missing data (B)

Figure 6 by © Hoare et al. 2015 licensed under the terms of the Creative Commons Attribution License
3.5 Trends

All three pairs of charts revealed the following trends. When missing data were excluded, home was the majority preferred place of death of the study population in 53 of 65 reports. However, missing data accounted for as much as 87% of preferences in one report [51] and for 50% or more of preferences in a further 17 reports. When missing data were included, home was the majority preferred place of death of the study population in only 36 of 65 reports. Studies of the general public reported little missing data and consistently reported home as the most preferred place of death, with preference for home across these studies only ranging by 19 percentage points.

4 Discussion

The review shows that when missing data were excluded, the majority of participants preferred to die at home. However, when the large amount of missing data were included in the analysis, it could not be stated that home was known to be where most participants with cancer or other conditions wanted to die. Preferences for place of death appeared to largely reflect where participants were cared for but not necessarily their medical diagnosis. Participant preferences for home seemed to be far more heterogeneous than those expressed by the general public, as demonstrated by the wide range of different values for home preference by participants. Neither the general public nor family caregivers appeared to be accurate proxies for patients’ preferences for place of death. In the next section, I explore the potential reasons for each of these trends.

4.1 Missing preferences

The ‘missing’ preferences are likely to represent preferences that were not asked or not expressed. Preferences not asked may reflect the difficulty for clinicians of initiating end-of-life conversations for a variety of reasons, including difficulty accurately prognosticating a patients’ death, concern about upsetting the patient and discomfort in discussing clinical uncertainty with a patient [58]. Recognising that end-of-life patients are sometimes considered a ‘vulnerable’ population, it is likely that some studies will have excluded those closest to death [59]. Other participants will not have been asked their preference because they were considered too ill to be able to provide it, including participants who were cognitively or physically impaired from communicating their preference [60]. Other participants’ preferences are likely to be missing because they did not wish to express their preference for a variety of reasons.
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Many of the ‘missing’ preferences are likely therefore to denote unrecorded preferences for death in any setting, but it is also likely that some will have had no preference. This could be because of the complexity of place of death decisions, as outlined in the introduction, and may also reflect ambivalence about where they die. Some of the included studies reported a significant minority of patients were undecided about where they wished to die (e.g. [32, 60]). Waghorn et al. [50] found in their review of cancer patient priorities that place of death was a less important issue compared to other factors associated with a ‘good death’, such as adequate pain and symptom management and not being a burden to family members. Regardless of the reasons, the exclusion of ‘missing’ preferences from study reporting inflates the significance of recorded preferences and, critically, challenges the contention that hospital is inappropriate because patients do not want to die there.

4.2 Understanding difference in preference for place of death

The data reveals that across all disease groups, including cancer, it could not be stated that the majority of patients wished to die at home, when missing data were included. The pervasiveness of the trend is pertinent given the current policy focus on home, and the historic focus of end-of-life care on the needs of cancer patients [1]. Over the next sections, I consider this further by addressing the trends in the dataset.

The variance we found between the preferences of the general public and patients is reported by others [28], and could in part be explained by differences in data collection. For example, information from the general public was often drawn from large surveys whilst patient preferences were often collected from patient records. The dissimilarity between public and patient preferences also seems likely to be partly attributed to the different meanings given by respondents to questions about preferred place of death, as outlined in the Introduction.

Family members’ proxy reports of deceased patients’ preferred place of death, contained a large amount of missing data. Whilst the discrepancies between patient and family perspective could be due to compromised recall because of the period between bereavement and when participants are asked to take part in research [61], it seems likely that not all relatives will have known the deceased wishes, because the patient had not shared it with them [62]. This reluctance to disclose their preferred place of death to relatives may be for some because they did not want to burden their relatives with the need to fulfil their wish [17, 63], or from concern about discordant views [64].
Where participants wished to die appeared broadly associated with where they were asked about their preferred place of death. The association could suggest that preferences are contextualised by patients’ experience of care; whether of a previously unknown place, like hospice [60] or because some patients prefer familiarity over change at the end of life [65].

4.3 Limitations

I cannot report more than inferences about the missing data, due to a number of limitations of the dataset. I explore these problems in turn below.

The extent of missing data in studies is likely to be underrepresented, as our calculations for missing data were limited to ‘reported’ missing data, where population and sample sizes were detailed. Public opinion surveys in particular were likely to not report the number of participants who did not answer the question, which may explain some of the difference between the homogeneity of public preferences compared to the heterogeneity of patient preferences. Likewise some audit studies did not report how many records they viewed which did not have information on preferences (e.g.[66]). In studies where only a set number of responses were reported (e.g.[67]), it was not possible to know how many participants were not asked their preferences. In some papers where only weighted preferences were reported the proportion of ‘missing’ data is estimated.

It is not possible to speculate on where the ‘missing’ participants would have preferred to die, because the distribution of these preferences is unknown. They could represent preferences for any location, or a participant not having a preference. When the missing data were included, the proportions of preferences for all locations were reduced. Consequently, of the known preferences, the majority of respondents still preferred home over other locations as a place of death, thereby supporting the current policy focus. However, this interpretation overlooks the scale of the missing data.

The heterogeneity of the sample of patient and carer studies may explain the variations of the responses identified, rather than being an inherent feature of these preferences for place of death [28]. The association between where participants were asked about preferences and their preferred place of death does not imply causality; participants’ for instance may have been in their preferred place of death. Similarly, whilst preferences for place of death data was used where possible, the findings do conflate preferences for place of death and place of care. Whilst recognising that they are not synonymous preferences [68], our use of place of care data reflects evidence from practice, whereby
answers about place of care provided in a clinical context were sometimes used as a proxy for place of death (e.g. [44]).

5 Conclusion

The substantial amount of missing data found in the review means it is unclear what proportion of patients wish to die at home. In practice, preferences for place of death seem to depend on who is asked the question; what, where, why and when they are asked; and how those without an answer are included. Whilst we found no clear difference between preferences for home and the diagnosis of patients, there was a discord between the reported perspectives of the general public, family members and those of dying patients. The results suggest that patient preferences may be contextualised by where participants are being cared for when they are asked about where they want to die. The latter is important for understanding end-of-life hospital admissions, because it suggests that hospital is not always an ‘inappropriate’ site of death.

The results of the review challenges the common assertion that the majority of patients wish to die at home, and I explore in chapter 6 why home may not always be a desirable place of death. This finding has implications for understanding hospital admissions at the end-of-life, given that meeting patient choice is a central justification for reducing the proportion of hospital deaths and consequentially also admissions. It raises the potential significance of other factors recognised to be related to the aim of reducing end-of-life deaths in hospital, such as cost and expectations of hospital care [6]. To explore this, I turn to consider in the next chapter the social, historical and political context of end-of-life admissions.
Chapter three

“There is no doubt that taking steps to enable people to keep out of hospital at the end of life is in the interests of dying people and those important to them, and in the interests of the NHS. Commissioners can reduce the costs of emergency admissions by facilitating people to remain out of hospital, or to be transferred from the hospital as soon as possible, if they have no wish or clinical need to be there.”

[69]
Chapter 3

The not-good place of death: hospital in UK end-of-life care policy

The conceptualisation of ‘inappropriate’ hospital admissions at the end of life is the product of two strands of health policy. First, in the history of hospital provision, and later palliative care, the place of the dying in hospital has often been difficult. Second, across the persistent interest in hospital admissions, there has been a strong focus on the acutely sick.

In this chapter I explore these two strands. To untangle the rhetoric that surrounds death in hospital and which informs the perception of end-of-life admissions, I start at the establishment of the hospital, and taking a chronological approach, I pause to consider the relevant changes in health policy and palliative care. I explore in detail the 2008 English End of Life Care Strategy (EOLCS), which signalled the inclusion of end-of-life care into general health policy and which remains a key reference for understanding end-of-life care. I conclude this section by considering recent policy developments which contribute to the ‘inappropriate’ framing of end-of-life hospital.

Building on the previous section, I next explore hospital admissions in the UK. I begin by examining the justification that makes hospital admissions a pressing policy concern: an ageing population, rising admission rates and trends in place of death. Next I consider problematic admissions in non-end-of-life contexts. I conclude by exploring the apparent undesirability, cost and ability to prevent end-of-life admissions and existing resolutions. Across both sections I aim to outline the multiple perspectives and structural influences which contribute to making hospital admissions ‘inappropriate’.

1 End-of-life care policy
1.1 Pre Strategy: Anywhere but hospital
1.1.1 The hospital

The conception of the hospital in the centuries since the first Roman field hospitals has flexed and changed to address the needs of its dependants [70]. Across these changes, dying patients have necessarily been a ubiquitous, and frequently denigrated, aspect of
English institutional medical provision. Understanding how the terminally ill have been accommodated provides historical context to contemporary conceptions of hospital as a place of death.

Reliable hospital records start from the end of the Norman conquest, and suggest that monasteries and royalty were establishing hospitals to care for their dependants, often the elderly [71]. In the twelfth and thirteenth century, hospitals proliferated, but many were selective, often focusing care on patients thought likely to recover, with the terminally ill often excluded [71]. Today, two of these ‘ancient hospitals’ remain, the others being decimated by causes including economic depression, the black death, and the dissolution of the monasteries [71].

The beginning of the modern hospital can be found in the eighteenth century, when voluntary hospitals were established by wealthy benefactors [71], often with strict criteria about who was admitted, with evidence that ‘incurables’ were excluded [72]. A new scientific and practical approach to medical research established in Paris [73] lead to a rapid increase in hospital provision in the nineteenth century and offered for the first time an attractive alternative to being cared for at home [70, 74]. Whilst many died within these institutions, they often did not admit those recognised to be dying, following earlier form. ‘Incurables’ were not accepted because they could not help to secure the charitable donations which these institutions were dependent on, since their admission promoted neither a favourable turnover nor outcome of patients, and nor were they considered useful in either researching or teaching medical practice [70, 71, 75, 76].

The need to provide care for the dying, however was recognised in the late nineteenth century, with a small number of ‘dying homes’ established. These provided the first examples in England of institutional specialised dying care [76, 77], and followed the establishment of similar hospices in Ireland, Germany and France [78]. A minority of specialist voluntary hospitals were also beginning to openly accept dying patients, with the first cancer hospitals, and cancer wards, set up at the end of the 18th century [79].

For the majority though, death typically either occurred at home, or for the poor in workhouses [79]. These institutions, first established following the 1601 Poor Law, proliferated after the 1834 amendments and accommodated the poor sick, the old and the chronically ill within the workhouse itself and later within workhouse infirmaries [72]. The workhouses offered bleak respite, with little nursing provision beyond that provided by inmates themselves and on the whole, unsuitable conditions [70].
number of workhouse infirmaries increased in the early twentieth century, and the expected standard of care improved [70], but by the time of the formation of the National Health Service those still considered Poor Law infirmaries were reported to provide minimal care in dismal settings [71]. These institutions continued to typically provide care to the elderly and the chronic sick, with the voluntary hospitals and newer municipal hospitals primarily providing acute and short-term care [71, 72]. Even within Poor Law infirmaries though, the place of the dying on wards was not secure and could be challenged as an 'abuse' of the facilities [70].

During the second world war, as in the first, military patients were prioritised over civilian patients [70] and as a consequence the long-term sick and elderly patients were often refused admission where possible [72]. Predicting the war, civil servants in the 1930s had begun to plan for the unification of the disparate healthcare system so as to be able to best respond to the casualties expected, which later became the foundation of the National Health System (NHS) [80]. The NHS policy of equitable health access from the ‘cradle to grave’ meant that for the first time, the dying were explicitly included in provision.

1.1.2 The hospice

The establishment of the contemporary hospice by Cicely Saunders at St Christopher’s in 1967, also challenged the desirability of hospital deaths. Developed in part to meet concerns over deaths in hospital [81], it provided an alternative place to die whilst also shaping provision. Palliative care, first practised within the hospice, is fundamental to end-of-life care, with the roots of contemporary policy beginning with the hospice movement [82]. I consider next relevant aspects of this history to further understand ‘inappropriate’ end-of-life hospital admissions.

Cicely Saunders pioneered the idea of ‘total pain’: consideration not just of physical distress but also mental, emotional and social too [21]. This holistic approach has become fundamental to the palliative care ethos [83] and at the time appeared antithetical to hospital provision. Hospitals were described as “appear[ing] to be trying to cure all of their patients and failing in a high proportion of patients” (Bailey, 1959 cited in [77]). (For discussion on contemporary care see section 2.2.1).

‘New’ hospices proliferated in the following decades, founded by local charities [77]. Reflecting this expansion, in 1987 formal recognition of the needs of dying patients
occurred with palliative medicine established as a medical speciality and the NHS required to consider end-of-life care provision [84, 85]. Whilst the growth of the specialism of palliative care undoubtedly improved care for dying patients, the maintenance of its association to hospice care meant that it was inevitably constructed as something distinct to hospital provision.

This theme persisted, whilst the link between palliative care and cancer care (the disease focus of the new hospices) was slowly uncoupled. The Calman-Hine report [86] called for better integration within cancer care [77], but also included a recognition of the need for palliative care for non-cancer patients [87]. The Department of Health responded in part in 2000 with the NHS Cancer Plan which included a pledge to increase spending on palliative care to match that of the hospices ([88]p.7). By 2003, the need for access to palliative care for all patients, regardless of diagnosis was formally recognised in a white paper [89].

The 2003 white paper also established home as the standard for dying in end-of-life care policy. The paper emphasised patient choice, particularly for place of death: “We wish to offer all adult patients nearing the end of life, regardless of their diagnosis, the same access to high quality palliative care so that they can choose if they wish to die at home” ([89]p.44, my emphasis). This potent combination of patient choice and place continues to be a feature of end-of-life care, and challenges the role of the hospital in providing terminal care.

The exclusion of hospital as a place to die continued as government interest in end-of-life care grew. The first NICE guidelines [90] (published in 2004), the NHS End of Life Care Programme [91] (ran from 2004-7) and the promise for more funding for palliative care [92](2006), all placed a focus on place, respectively outlining that model care occurred at home8, highlighted the undesirability of death in hospital9, and tied outcomes to greater patient choice, and thus home. 2007 established end-of-life care as a priority in the NHS next stage review[93], paving the way for the EOLCS.

Dying has always occurred in the various forms of the hospital, but the place of the dying patient has varied. Frequently problematic, the distinctiveness of the dying was often derived from an emphasis on the hospital as a provider of acute care. This legacy seems likely to have influenced the current conception of hospital as an ‘inappropriate’ place of death. The modern hospices have been transformative in end-of-life care, but as institutions for the dying patient, have also challenged the appropriateness of hospital in
dying. The recent policy emphasis on choice reinforced this, and critically, continues to be a pertinent focus.

1.2 End of Life Care Strategy: Home and choices

2008 brought the publication of the EOLCS[1], which, through a continued emphasis on place and choice, cemented the exclusion of hospital as a desirable place of death. In the following section I explore some of the ways in which this was established, focusing especially on the ‘pathway’ approach to organising end-of-life care.

The strategy sought to systematically address end-of-life care for adults10. It centred on care for the patient and the care needs of the patients’ informal carers (friends and family), who were recognised to hold an important role in supporting a patient to die at home ([1] p.14). The strategy aimed to “bring about a step change in access to high quality care for all people approaching the end of life [...] Implementation of this strategy should enhance choice, quality, equality and value for money” ([1]p.33). These factors were thought to coalesce in deaths at home, particularly in comparison to hospital deaths. The ‘whole systems’ approach of the strategy meant in practice that the ethos of hospital as antithetical to end-of-life care extended to all services and settings that care for dying patients.

1.2.1 The End of Life Care Strategy Pathway

The EOLCS centred on a six-step Pathway (Figure 6) to organise a patient’s journey from the point of identification as ‘end-of-life’ through to death, and beyond in the form of appropriate after-death care. Reflecting the implicit linearity of the term pathway, it offered a consecutive approach to the organisation of end-of-life care, with each step building upon the last. As such, the Pathway began with discussions with the patient about their ‘end-of-life’ status, followed by an assessment of their preferences about how and where they want to be cared for and to die. Using this information it was expected that healthcare professionals would realise these preferences through the coordination and delivery of appropriate services. When individuals reached the ‘dying phase’ – as identified by healthcare professionals - appropriate care should have been put in place for the last few days of life. Finally, the Pathway included after-death care, including sensitive care of the body and support for bereaved family and carers.

The Pathway presumed that patients wish to die at home, and positioned hospital in opposition to this (see section 2.2.1 for further discussion). Hospital is marginalised from
step one of the Pathway and this position is entrenched in subsequent steps such that
death in hospital came to symbolise preferences not appropriately sought, services not
coordinated, and provision not delivered. Further discussion of this continues below
(section 2.3).

Figure 6 The End of Life Care Pathway

1.2.2 Choosing home

If death is to occur in the community rather than the hospital, the home must be
refashioned as a medical site, with care prearranged and brought in. The Pathway
provides a vehicle for this, presuming that patients can anticipate their own needs, care
can be coordinated ahead of time and, critically, the deterioration to death can be
predicted [94]. To achieve this, the EOLCS advocated that patients and their healthcare
practitioners participate in advance care planning, whereby a patients’ needs are
assessed, their preferences discussed and a care plan created which reflects these choices ([1] p. 12).

This emphasis on patient preferences reflects a wider choice agenda in the NHS. The 2010 white paper [95] sought to establish greater patient involvement in healthcare. The subsequent consultation paper repeated the rhetoric of the Strategy by stating a commitment to “establishing a national choice offer for people and their families to be able to choose to die at home, including care homes” ([96] p. 31 para 5.36), a choice that has persisted throughout subsequent end-of-life care policy (for further discussion see 2.2.2).

To facilitate discussions about choice, the strategy advocated the Preferred Priorities of Care document, which continues to be used. It is generally a paper document held by patients that outlines their end-of-life preferences, with completion facilitated by a healthcare professional involved in the patient’s care, and input where relevant from the patient’s family or friends. It is an ambiguous document which does not distinguish between where patients wish to die, and where they wish to be cared for prior to this, which is important because patients do distinguish between these preferences [68]. In addition to the nuances in end-of-life preferences identified in chapter 2, this has potentially significant consequences for advance care planning. These consequences and the presumption that there will be time and space for healthcare staff to coordinate this process, are discussed further in chapter 6.

Place of death has remained fundamental in the assessment of quality in end-of-life care, challenging again hospital as a place of death for end-of-life patients. The focus of the quality measure has varied over time, from home, to “usual place of residence”11 and latterly to hospital [5, 9, 97]. Common to each measure has been the logic that quality can be measured through the fulfilment of patient choice in place of death, which is presumed to either be for home or for anywhere else but hospital. Whilst the fallibility of this measure has been recognised (e.g. [26]), it has persisted in part because it can be easily collected from routine data. The subsequent regular assessment of where patients’ die reinforces place as a critical aspect of UK end-of-life care and thus the involvement of hospital as problematic.

Despite the clear alignment between the choice rhetoric and the emphasis on home in end-of-life care, choice can also be used to challenge the home agenda. A preference for hospital can transform an ‘inappropriate’ location into an appropriate one. For instance,
the NICE Quality Standard [98] aims for the “reduction in unscheduled care hospital admissions leading to death in hospital (where death in hospital is against their stated wishes)” (my emphasis). Such dissonance is however reportedly rare, and the guiding message of the EOLCS was clear. Dying should occur at home or care home, possibly in hospice, but not in hospital.

1.3 Post Strategy: the removal of hospital

Government publications on end-of-life care have increased following the publication of the EOLCS[12]. In the following section, I explore the post-EOLCS landscape, tracing through the key documents how the concept of ‘inappropriate admissions’ has persisted. Inherent in each of the documents outlined is a tension between what is considered clinically appropriate for the patient at the end-of-life (home care), what is politically desirable (greater care provided in the community) and a concern for financial prudence (reduced hospital use), which coalesce in an interest in reducing end-of-life hospital admissions. Together, each paper or report has contributed to the persistent recognition that hospital should not be where patients die.

1.3.1 Transforming hospitals

‘The route to success in end of life care - achieving quality in acute hospitals’ (RTS) was published in 2010 and sought to achieve three things; 1) improve the care of those dying in hospital, whilst also 2) preventing deaths in hospital through improved discharge and 3) “reducing inappropriate and expensive emergency hospital admissions” through greater community coordination ([99] p.2, p.10), my emphasis). RTS was revised in 2015, responding to the developments that arose from subsequent reports, many of which are highlighted below [100]. To improve care the revised RTS recommends five tools, of which only one, the AMBER care bundle[13] was targeted solely at improving hospital care [100]. This in part reflects the broad scope of the other tools, which were not specific to any particular setting, as well as the triple aim of RTS. However, it also suggests that improving hospital care in end-of-life care may have been a lesser goal over enabling more patients to die at home, thereby contributing to the awkward place of hospital, and thus admissions, in end-of-life care.

1.3.2 NICE Quality standard for EOLC

In November 2011 the first NICE Quality Standard for end of life care [102] was published. The Introduction restates the discrepancy between preferences for home and
the high proportion of hospital deaths, and supports measures in the EOLCS to increase the latter, in turn adding to the problematic perception of hospital at the end-of-life. Reflecting the need for the Standard to be relevant to all settings, there are few other references to hospital or other places of death. The Standard was amended following the withdrawal of the Liverpool Care Pathway (LCP), the coverage of which contributed to the cultural discourse about hospital deaths, adding a moral imperative for the reduction of hospital admissions.

1.3.3 LCP ‘scandal’

A new normative challenge of death in hospital arose following extensive media coverage in 2012 about the apparent misuse of the LCP, a tool intended to provide best hospice practice for patients dying in other settings [103]. Promoted within the EOLCS, the LCP was widely adopted by hospitals, with over 80% of trusts using it [1]. A media furore however developed over the use of the LCP [104], eventually leading to an independent review. The subsequent report [105] in July 2013 found that the LCP in many instances was not being properly implemented, and as a consequence, was leading to poor end-of-life practice. The report was a damming critique of end-of-life care in hospitals with concerns including a lack of respect towards patients, the withholding of fluids, the overmedication of patients, and a lack of meaningful consultation with patients or families. The report concluded that the LCP should be withdrawn from use and made a number of recommendations to address the perceived failings [105]. In response, the “Leadership Alliance for Care of the Dying People” was formed, comprising representatives from relevant national organisations and charities. In July 2014, the Alliance issued five priorities for the care of dying patients [106] which broadly reiterated aims of the EOLCS but differed in providing a “shared vision” to all those involved in end-of-life care [107]. The LCP furore made it apparent that where and how people die was of moral significance, and contributed to the normative incentive for reducing admissions: a hospital death could be a ‘poor’ death.

1.3.4 Health and Social Care Act 2012

The Health and Social Care Act 2012 (HSCA) was widely announced as the most significant change to the NHS since its formation (e.g. [108]), but it has had limited consequence for the appropriateness or otherwise of end-of-life admissions.

The consequence of the HSCA meant that the Department of Health no longer gave policy direction, only providing a “Mandate” or direction for the NHS, with end-of-life
care now the responsibility of NHS England. At least partly in response to these changes, plans to update the EOLCS were cancelled [96, 109]. It also meant a move from ‘process’ driven targets to outcomes focused targets [110, 111], and as a consequence, further cemented the use of place of death as a measure. Outcome targets present a problem to end-of-life care, which is not a field where outcome measures are easy to derive, death unusually being not the worst outcome as in most other fields, and therefore where the tangible nature of place is particularly valuable.

The changes brought about by the HSCA did not however change how end-of-life admissions were viewed, with a continued vision in general health policy for more ‘out-of-hospital care’ and fewer ‘avoidable’ admissions for care home patients through greater collaboration of health care services and social care ([112] p.4, 24). For end-of-life policy, the persisting focus on place and choice, enacted through home as a preferred place of death, is evident in the reports outlined below (for further discussion see section 1.3.10).

1.3.5 Actions for End of Life Care: 2014-16

NHS England published in November 2014 an intermediary paper [113] whilst a 5 year plan was designed. Reflecting the consternation about the LCP, end-of-life care was reconceptualised from a ‘pathway’ to a ‘house of care’ model. The move implies a more holistic, less process driven and linear view of end-of-life care. However, whilst the publication was designed to “signal a shift in focus from ‘place of death’ to the broader ‘experience’ of end of life care” (p.6), there remained a drive to have fewer patients in hospital ([113]p.13). Hospital was thus still an ‘avoidable’ phenomena ([113] p.13) and as a consequence, the hospital still an inappropriate place of death.

1.3.6 Independent review of choice at the end of life

In February 2015 a review was published [114], responding to the ‘national choice offer’ mentioned earlier. The review echoed calls in the Actions paper to forward the policy and practice focus about end-of-life care beyond place of death, and like the above reports, concluded with similar recommendations. However, the rhetoric about hospital from the EOLCS was retained; hospital care should be reduced, ‘unnecessary’ admissions avoided, and the resulting savings invested into community provision ([114] p. 7). The emphasis on patient choice (emphasised by the call for a wider end-of-life care discussion) is thus enacted in practice as a choice for anywhere but hospital.
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1.3.7 Ambitions for Palliative and End of Life Care

In September 2015, a follow-up to the 2008 Strategy was published by the National Palliative and End of Life Care Partnership[109]. The document aims to build on the success of the strategy by “improving outcomes, including people’s experience and quality of care, wherever the setting” ([109] p.6, my emphasis), and presents a significant shift in end-of-life care policy, both in rhetoric, away from place, and in how practically change is to be achieved.

The document focuses on addressing inequity in the quality of end-of-life care. The ‘vision’ of the strategy is to ensure that the reality for every end-of-life patient is that “I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carers” ([109]p.9), a statement derived from collaborative work between end-of-life care organisations and NHS England. The Ambitions document is similarly the product of a partnership between 27 stakeholder organisations, reflecting the change in policy landscape following the HSCA. The document is subtitled a ‘national framework for local action’ and states explicitly that, unlike the EOLCS, it is not seeking to dictate practice but rather to engender community-based leadership to facilitate change. As a consequence, the document focuses on broad ‘ambitions’ which ‘local leaders’ are expected to use to plan local service delivery (p.7).

The six ambitions of the document are outlined in Figure 7. They demonstrate a wider scope compared to earlier policy, extending to expectations for lay communities (ambition 6) as well to the conduct of individual staff (ambition 5). Many of the prominent messages of the EOLCS are though maintained, with a continued emphasis on patient choice (ambition 1, 4) and discussions about, and planning for, the end of life (ambitions 1, 3, 4). The form of this planning is however less prescriptive than presented in models such as the EOLCS Pathway, and thus allows greater scope for the inclusion of hospital.
Reference to place in general is more nuanced in comparison to earlier policy material, with a distinction made between place of care and place of death. The aim of ensuring parity of care in all settings results in infrequent explicit mentions of ‘home’ and ‘hospital’ and reflects the Actions call to move the focus of end-of-life care beyond place. However, there is evidence that the sentiment that hospital is an undesirable place of death for end-of-life patients is still applicable. The Introduction references the “significant progress” ([109]p.6) in reversing the proportion of patients dying in hospital, whilst enabling more patients to be cared for in the community remains a key justification, in turn implying that ideal end of life care should not occur in hospital.
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1.3.8 NCPC: Getting Serious About Prevention

The National Council for Palliative Care (NCPC) published in October 2015 a report on reducing hospital admissions for end-of-life patients in order to achieve more community care. The report justifies its focus financially: fewer hospital admissions would result in NHS cost-savings including reducing pressure on staff time and bed space. A second justification, less explicit, was that fewer admissions would lead to a better experience for patients at the end of life and their families. This was made by referencing an earlier argument: patients do not want to be in hospital at the end of life, and dying at home offers a ‘significantly better’ experience ([69] p.4). As before, hospital is seen as somewhere patients neither wish nor need to be, nor where patients receive the best care.

1.3.9 NICE guidelines: care in the last few days of life

In December 2015, the first NICE guidelines about care in the last few days of life were published[115], in part as a response to the removal of the LCP and the ‘tick-box’ end-of-life care it was denounced as promoting[15]. They have been described by those who wrote them as “common-sense” [116]16, echoing the “simply good care” description of the ‘Priorities of Care’ by the Leadership Alliance for the Care of the Dying People [107]. This seems likely in part because of the limited reference to specific medical treatment or provision, which importantly implies that there are few medical justifications for the admission of end-of-life patients to hospital for end-of-life care. As such, it contributes to the position that hospital is not where dying patients should be.

1.3.10 ‘Our Commitment to you for end of life care’

The Department of Health [5] published its response to the Choice review (see section 1.3.6) in July 2016. The document recognised and built on the Ambitions paper through similar ‘commitments’ to the individual end of life patient (Figure 8), with the aim of ensuring “everyone approaching the end of life [will] receive high quality care that reflects their individual needs, choices and preferences” (p.7). It signalled a change to earlier publications however by explicitly including place and by recognising that deficiencies in care at the end-of-life can occur in both the hospital (poor care delivered without patient dignity or respect) and at home (inadequate pain relief).

The persistent focus on patient choice and place of care was however maintained, echoing the focus on end-of-life care in the government’s mandate to NHS England [117].
Given this context, it is unsurprising that hospital admissions are mentioned as ‘unnecessary’ and something which can be ‘avoided’ with earlier planning and eliciting of patient preferences ([5]p.25-26).

Figure 8 'Our Commitment to you'

```
Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:

- have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die;
- make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families;
- develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness;
- share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care;
- involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care;
- know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way.
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1.4 Care today

End-of-life care in the UK is provided in a variety of settings, across which the control of access to hospital is a key theme. Below I outline this argument by considering the three main types of care for end-of-life patients, thereby concluding the review of end-of-life care in policy and the first half of this chapter, and providing context to the empirical descriptions of end-of-life care that occur in the next chapters.

1.4.1 Social care

At the end-of-life, the line between a patients' social and health care needs is often blurred, so it is perhaps expected that hospital is not deemed to be a suitable site for care. Social care at the end of life is provided rarely by the NHS but instead by a combination of local authority and private care agency providers, with free or subsided provision need- and means- tested. The exclusion of social care from the NHS has been
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acknowledged as a problem within end-of-life care [121] and there have consistent calls for free care to be available to all at the end of life ([122]p.8). Much community social care could hypothetically be fulfilled by the hospital, given that an in-patient admission, in addition to healthcare, involves personal care, meals, and a bed. Successive governments have unsurprisingly been keen to emphasise that this is not the role of hospitals for end-of-life care patients or otherwise. This is perhaps best demonstrated by the persistent condemnation of ‘bed-blockers’: hospital patients, often elderly, for whom it is no longer considered necessary to be in hospital but who cannot be discharged because community social care provision has not been arranged [123].

1.4.2 Health care

Most end-of-life care in the patients’ final year of life is provided in the community, punctuated with, on average, between 2 to 3 hospital admissions [124]. Community care is provided by the patients’ general practitioner (GP), often supplemented, particularly for cancer patients, with support from a Macmillan Nurse or Clinical Nurse Specialist[18]. Hospices provide specialist palliative care, with care historically focused on cancer provision. Reflecting the relatively small number of beds available, inpatient hospice care is typically reserved for patients with significant physical or social, psychosocial or spiritual needs [125]. Whilst hospices can provide terminal care, their focus is symptom control and approximately half of all inpatients are discharged and subsequently die elsewhere [125].

GPs act as gatekeepers to hospital, facilitating admissions or access to a hospital specialist only for patients considered appropriately in need [126]. Patients may additionally access hospital care themselves through the hospital Accident and Emergency departments (A&E) which act as a threshold to inpatient care, or by out-of-hours GP services. Any patient-instigated admission is considered unplanned, and are defined as ‘emergency admissions’ by the NHS [127]. In turn, this implies that end-of-life admissions must occur because patients require specialist or acute care, and if not must therefore be ‘inappropriate’.

1.4.3 Trends in place of death

Hospital care for end-of-life patients disproportionately occurs towards the last month of life [124]. Of those patients who do die in hospital, most (89%) are likely be admitted as an ‘emergency’ admission [128]. Deaths in hospital typically occur within a month of admission, with many occurring within the first three days (Figure 9).
Death in hospital is patterned by age and diagnosis as shown in Figure 10, whereby patients are more likely to have respiratory and circulatory conditions and to be older (except the oldest-old, for whom a smaller proportion die in hospital than those aged between 65-84 years) [4]. These figures ignore however that many patients have multimorbidities, a phenomenon that is growing [129] and increases the likelihood of hospital admissions, thereby potentially challenging the recent trend of decreasing hospital deaths [130].

Figure 9 Deaths in hospital by length of stay

![Deaths in hospital by length of stay](image)

Figure 10 Graphs of place of death

![Place of death by age](image)
Hospital has remained the most prevalent place of death in the UK for the last five decades, with fluctuations (a range of 11 percentage points) (Figure 11). Home by contrast, has had a clear downward trajectory until the mid-2000s, with fewer dying at home almost year-on-year. It seems plausible that it is this trend that galvanised end-of-life care supporters to advocate for greater emphasis on place of death, rather than a particular concern for hospital deaths (see also section 2.1.1).

Figure 11 Trends in hospital and home deaths

2 Hospital admissions

It is clear that over time hospital has had little place in the ideals promoted by end-of-life care policy. Hospital admissions by contrast have received increasing exposure, in
both health and end-of-life care policy. I draw on both of these domains in this half of the chapter to disentangle the assumptions that contribute to the perceived inappropriateness of end-of-life hospital admissions.

I start by exploring the demographic and epidemiological context identified by policy to justify increases to the proportion of ‘inappropriate’ admissions, and then consider wider trends for decreased hospital provision. I find that whilst demographic changes have been used to provide an impetus for addressing admissions, the link between these and increasing admissions is not as straightforward as presented.

Next I explore three of the main reasons why end-of-life admissions are perceived as a problem in policy; 1) home is a ‘better’ place to die, 2) admissions contravene patients’ preferences and 3) admissions are expensive and divert funding away from improving end-of-life care provision in the community. These in turn contribute to the labelling of admissions as ‘Undesirable’, ‘inappropriate’, ‘expensive’. Across this topic I find evidence that in concert with the stated concern for enabling patient choice, political pressures for reducing hospital capacity and restraining healthcare budgets are likely to be factors in the government interest in end-of-life hospital admissions.

I conclude by considering the ‘unnecessary’, ‘preventable’ and ‘avoidable’ nature of admissions by exploring the explanations that have been given for these admissions, and the suggestions for ‘preventing’ or ‘avoiding’ them. In doing so I challenge the normative values given to places of death and the dichotomous framing of home and hospital, critiquing the blanket negative labelling of end-of-life admissions.

2.1 Background trends
2.1.1 More old, dying longer and alone

Demographic changes in the UK are used in policy documentation to justify and explain the recent interest in end-of-life care, and consequently the desire to reduce end-of-life hospital admissions. I argue in the following section however that these changes are not always as clearly aligned with hospital admissions as often presented, thereby challenging the notion that end-of-life are admissions necessarily ‘inappropriate’.

Britain is described as an ‘ageing society’: the median age of a citizen is now older than it has ever been, partly attributed to increases in life expectancy ([4, 135] p.9), in turn due in part to changing patterns of illness. Population wide changes in mortality from predominantly infectious and communicable disease to chronic conditions are occurring,
and like population ageing, is a global trend across high-income countries [136]. These demographic and epidemiological changes exercise policymakers in part because it means providing end-of-life care to an increasing number of people, and for longer, with significant resource and capacity implications. The most recent government document on end-of-life care for instance states that “Around 470,000 people die each year in England and this is projected to rise by 20% over the next twenty years. We also expect more people to die at an older age and have more complex needs. [...] As a country, we face an unprecedented challenge to ensure that the NHS and care services can respond to these changes.[5]” These changes have helpfully been used to create a powerful impetus for health reform - including end of life care - and by emphasising the pace of change, an urgency for these reforms to be made [94]. However, they seem likely to also have contributed to the negative interest in hospital admissions, with predictions for increased numbers of deaths in hospital and fewer at home if current practice was not amended [137]. Given this context, it is useful to explore possible alternative understandings of these changes.

What is often missing from arguments about a “silver tsunami” [138], however, is that the growth of the elderly population is not limitless but will peak and then reduce as the smaller proportion of younger age groups grow older ([139] cited in [140]). Furthermore, whilst it is often presumed that the combination of an increasing proportion of older people to a decreasing proportion of working age people ([135] p.8-9), will lead to a greater burden to the NHS and associated services (e.g. [141]), the association is not straightforward. Spijker and MacInnes [142] for example argue that the proportion of dependents has fallen in recent years, and is now expected to stabilise. Similarly, the idea that a greater number of older people must mean a higher consumption of health services is not conclusive. It has been demonstrated that the number of days spent in hospital (used as a proxy for hospital costs) did not increase with age per se, but with proximity to death [143]. Furthermore, whilst increasing age is recognised in government documents to lead to greater numbers of hospital admissions (e.g. p.34, [144]), there are important nuances. Currently, those aged 60-69 have one of the lowest A&E attendance rates by age group (Figure 12 (a)) and whilst rates rise sharply for age groups older than 80 ([145]), they only account for a small proportion of attendances because of the size of the group (Figure 12 (b)), a trend replicated in hospital admissions (Figure 13).
The increasing need for social care is however less ambiguous. When chronic disease becomes disabling, people seek emergency care from the hospital if help is not available elsewhere ([141] para. 25). With limited social support from government agencies (see section 1.4.1), and an increased emphasis on less institutional care, family care is relied on more [146], such that admissions can be linked to the ‘failure’ of family provision (see chapter 6, section 2.2). However, changes in household and family structure can make this difficult to provide [147]. More people are living alone or with only their spouse than in previous decades, particularly in old age ([148] cited in [147]; [149]). Adult children are less likely to live with [149], or near, their parents than previously ([148] cited in [147]) and this trend increases as parents age [150], making the day-to-day provision of informal care more difficult.
Figure 12 A&E attendance by age

(a) A&E attendances by gender and age group, 2013/14 (Annual rate per 1,000 population)

(b) A&E attendance by gender and age group, 2013/14 (Number of attendees)

Figure 13 Hospital admissions by age

2.1.2 Generally inappropriate: ‘emergency’ hospital admissions

The concern with end-of-life admissions is the latest iteration of over half a century of critical interest in hospital admissions. In the following section I consider ‘general’ admissions to show that it is not new to construct admissions as ‘inappropriate’ for some patients, nor to attribute a cost to them. I conclude by showing, through an analysis of
place of death trends, that dying in hospital is not a recent phenomenon but has persisted at a similar rate since the formation of the NHS. Together, this helps to untangle further the rhetoric about end-of-life admissions.

‘Inappropriate’ hospital admissions have consistently been linked with inadequate alternative community care, echoing contemporary arguments. Concern about the number of hospital admissions tracks trends in hospital capacity; as hospital bed numbers have decreased, so the interest in admissions has grown, with political interest in admissions since at least the late 1950s [152, 153]. Arguments were put forward as early as 1961 that admissions could be reduced if community care was improved [154], but a series of separate studies of hospital admissions over the decade found that whilst there were patients in hospital that were inappropriately located according to medical need, few of them could be cared for safely in the community with existing provision [154, 155]. In the 1990s, the number of studies on admissions proliferated, contextualised by concern about whether the reduced capacity of hospitals was meeting patient needs [153, 156, 157]. This research likewise stressed the inappropriate location of patients [156]. Moreover, it was shown that ‘inappropriate admissions’ were not objective but differed by location and on who defined the admission ([158]p.31).

Across this research, finance and hospital capacity have persistently been the justification for the interest in ‘general’ hospital admissions, whether in reference to bed days as in the early research (e.g. [159]) or more recent interest in inpatient waiting lists and other elective healthcare [160], and made pertinent by reference to current budget restraint (e.g. [144]). Whilst end-of-life care admissions are rarely explicitly associated with cost, it is apparent that this is a concern, whether in terms of capacity [31] (e.g. [161] p.39), or cost [27] (p.10) (see also section 2.2.3). The financial imperative for reducing admissions helps to explain further the political interest in end-of-life admissions, which is not wholly explained by reference to patient choice (chapter 2), and suggests interest in admissions is not exclusively directed by benevolent concern for patient wellbeing.

Today, general emergency admissions are divided between those considered acceptable - acute, unpredictable events, such as appendicitis or heart attacks- and potentially ‘avoidable’ ‘ambulatory care sensitive admissions’ which can, hypothetically, be treated in the community [162]. Hospital admissions have increased; in recent decades by nearly half, from 3.6 million in 1997-98 to 5.3 million in 2012-13 [144] [35]. The cause of the increase in admissions is currently attributed to patient practices for seeking urgent care, A&E department pressures (including the four-hour wait target) and problems in
primary care provision, as well as the demographic and epidemiological changes mentioned above [144]. Commentators suggest that whilst many ‘avoidable’ admissions are in practice not avoidable, end-of-life admissions may be with greater interventions [162]. The above research however suggests that ‘inappropriate’ end-of-life admissions may not be as tangible as policy suggests, nor so easy to address, but instead may be the result of complex social practices.

2.2 Admissions are ‘inappropriate’, ‘undesirable’, expensive

It is apparent from the above review that the idea of inappropriate admissions are not wholly justified by the official discourse about them. It is useful therefore to consider further why they are constructed as a problem, and I do so by considering the frequently used descriptors of admissions, ‘inappropriate’ and ‘undesirable’, and through these, an exploration of place, preference and cost. Throughout, I argue that successful recognition of the terms requires deployment of a number of culturally-held beliefs (hospital as a poor site of death), therefore challenging again the objectivity of admissions determined in policy documentation.

2.2.1 The problem of hospital

The perceived ‘inappropriateness’ of hospital admissions for end-of-life care patients is due to their associated increased risk of death in hospital. Whilst the EOLCS and subsequent documentation often state neutrality about specific places of death (e.g.[1]p.9, 33), the implication of policy is that hospital is not ideal. For example, the concept of a ‘good’ death cited in the EOLCS (Box 2) necessarily excludes hospital as a place where this can occur for all but frequent attenders, because of the emphasis on familiarity [1]p.9).

Box 2 EOLCS good death definition

“Although every individual may have a different idea about what would, for them, constitute a ‘good death’, for many this would involve:
• Being treated as an individual, with dignity and respect;
• Being without pain and other symptoms;
• Being in familiar surroundings; and
• Being in the company of close family and/or friends.”

[1]p.9
Other aspects of hospital care are also emphasised in the EOLCS to construe it as a less-than-ideal place of death, putting patients at risk of their dying status not being recognised, or recognised late, or not communicated, leading to patient and carer distress ([1]p.81). Hospital care is construed as being primarily focused on curative care, and therefore end-of-life patients are presumed to be vulnerable to receiving either invasive futile treatment ([1]p.57,65) or not having their symptoms adequately controlled ([1]p.80). In addition, the curative focus means that patients’ holistic needs are often ignored or not met ([1]p.81). Hospitals are understood as places where privacy is not guaranteed, and with a physical environment that is not conducive for either dying patients or their visitors ([164] p.17).

This negative perception of dying in hospital is also found in the popular press, and whilst particularly apparent during the media furore over the LCP (e.g. ‘Patients dying in hospital in pain and lacking dignity’ [165]), remains a topic of interest (e.g. ‘Cambridge professor reduced to tears by noisy hospital before death’ [166]). Its denigration can also be found in academic literature, which includes recognition of the noisy, busy and chaotic environment of hospital and its incompatibility with a peaceful death (e.g. [167, 168]).

This view of death in hospital often infers a negative comparison to home or hospice environments, where the converse of the above factors are considered to be either inherent or more easily achieved. Home is constructed in its most idealised sense; the strategy implies that at its best home fulfils the ‘good death’, which make it a place of familiarity, individuality and family. Whilst there are problems identified with home care, particularly in regard the availability of services, these are framed within a context of home being where patients want to be (see section 2.2.2). Hospice too is recognised positively, as a benchmark for end-of-life and palliative care ([1] p.28).

This is not to state that these views of hospital or other places of care are inaccurate, but that their often polarised construction means that there is limited space to recognise what every-day dying is like, or to accommodate occasions where home is not ‘good’ or hospital is ‘good’. There is also concern that it demonises hospital provision, to the detriment of patient and healthcare staff [169], with the potential for the rhetoric of hospital as a poor site of death to be become self-fulfilling (cf.[170]).
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2.2.2 The popularity of home

The presumption that patients want to die at home makes hospital deaths (and thus admissions) antithetical to patient choice, despite the lack of robust evidence. Whilst the emphasis on choice is something of a misnomer because access to the four choices given to patients - home, hospice, hospital and care home - is restricted, it remains important in understanding admissions. Fulfilling patient choice is recognised to be an important justification for labelling hospital admissions as ‘inappropriate’ for clinicians [16], and as outlined above (section 1.3), the discourse of choice is prevalent throughout end-of-life care policy. The mismatch between the discourse on choice, and patients’ ability to enact ‘choice’, or indeed whether choice is what they want at the end of life [173], in addition to the lack of robust evidence on preferences (chapter 2) suggests that the impetus to have fewer deaths in hospital is not wholly driven by a desire to fulfil patient wishes.

2.2.3 The cost of admissions

The Department of Health [1] considers end-of-life hospital admissions a ‘key element of expenditure’ of end-of-life care (p.15), calculated at approximately £750m each year (p.150), with each admission episode estimated to cost £2506 ([128] p.17). Reducing hospital admissions is proposed as a way to help fund improvements in community palliative care ([1]p.16). Whilst an in-depth consideration of the economics of admissions is beyond the remit of this thesis, next I explore briefly the feasibility of this proposal.

The financial benefits of reducing emergency end-of-life admissions were modelled in 2008 for cancer patients [144], finding a reduction of between 5-20% could result in between £16 - £66 million available for redistribution ([8, 144]p.31). The practicality of achieving this is however unclear. The Marie Curie “Delivering Choice Programme” provides one example, which sought to facilitate patient choice in place of death ([1]p.59). A financial assessment of the programme in one area however found that whilst the overall costs were comparable to existing care there were no statistically significant differences in the number of admissions [174]. The costs are likely to be greater because it excluded an assessment of the cost to family carers, which are recognised to be significant [175]. Another way to consider the financial benefit of reducing hospital admissions is to look at the cost of providing care in the home rather than the hospital. However, there is only limited evidence of costing home palliative care versus usual care, and inconclusive results in the research that had calculated it [176]. More broadly, it is
recognised that being cared for, and dying at home, does not necessarily involve cost-
savings compared to institutional care [177].

The lack of a direct association between reducing admissions and greater funding
resources for community provision matches the more established general admission
literature. This finds that cost-savings are difficult to achieve, primarily because most
‘inappropriate’ admissions require alternative provision if hospital is to be avoided [156,
158, 178]. When modelled, savings were only found with the most favourable
assumptions [178]. It is also unclear if transfer of costs from the acute to community
sectors are possible. To achieve this financial benefits would have to be: (i) greater than
the cost of expanding community provision; (ii) accommodate the predominately fixed
cost of hospital care; and, (iii) compensate for the economies of scale of providing care in
hospital to many end-of-life patients, versus individual care at home [156]. Moreover, it
is unclear whether reallocating resources from the acute to primary setting will be
possible on a large scale due to ‘institutional resistance’ and public hostility [179].

Overall then, current evidence shows it is uncertain whether reducing hospital
admissions will lead to health or social care cost-savings, but is likely to mean greater
costs for family and informal carers. Given the apparent lack of robust evidence for
overall cost-savings, the political interest in admissions may thus in part be explained by
the possible transfer of costs from the public sector to the individual patient and their
family.

2.3 ‘Preventable’ and ‘Avoidable’ admissions

Having explored the factors that are used to contextualise hospital admissions, I now
turn to consider end-of-life admissions directly, assessing how they are ‘preventable’ or
‘avoidable’. I consider first the existing evidence for why admissions occur. I argue that
current discourse means that admissions are inevitably negatively construed because
they are associated with the absence of best practice. I discuss second the suggested
resolutions to admissions. I show that whilst there are problems recognised with both
home and hospital as a place of death, they are weighted differently such that it is only
hospital that is considered a poor site of death.

2.3.1 Why admissions occur

Hospital admissions are contrary to ‘good’ end-of-life care according to policy, and are
typically framed as occurring within a dystopian environment of failing services and
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Crisis at home. Insufficient community services, particularly the absence of services during the night ([8]p.5) or poorly-coordinated care ([1]p.84) leads to admissions. Also contributing to admissions is inadequate communication with relevant parties and organisations, which means appropriate individuals are unaware when patients are deteriorating or when colleagues in other health settings have put care packages in place ([1]p.61). Overwhelmed family carers are frequently portrayed ([1]p.110) and are also linked to admissions whereby “individuals approaching the end of their life may experience worsening symptoms or a sudden crisis; anxious carers and family members will often call 999 for emergency support” ([180]p.3). Variations on these views are shared across charity reports (e.g. [69], which also highlight late identification of patients as further explanation for admissions) and academic literature on end-of-life care (e.g.[181]p.2). Since the measures recommended in policy to facilitate a patient being cared for at home are not contested, unplanned hospital admissions are necessarily construed as problematic because they are constructed as the culmination of failed end-of-life care, where policy recommendations have not been met.

However this construction of why admissions occur does not explain why some patients end up in hospital and others do not. The agency or volition of those involved, which may explain why care ‘fails’ for some patients and not others, is missing. Typically, those involved admissions are presented in broad tropes: the family carer willing to provide care but panicking, the patient prioritising place of death, and the healthcare professional organising care (or not). Necessarily however, all staff cannot be similarly experienced at organising care or predicting future care needs, nor all family carers able or willing to provide care, nor, as shown in the previous chapter, all patients wishing to die at home. Similarly absent are reference to pressures outside the remit of end-of-life care, such as financial constraints of generic community services. Excluding this ambiguity promotes clarity in policy, which is beneficial given the protracted process between the writing of the policy and its deployment [182], but its absence affects how admissions are understood.

The existing academic literature on admissions goes some way to addressing these concerns. It raises ideas that are anathema to the EOLCS: that some admissions occur because patients want to be cared for in hospital, and that for some patients, hospital admissions may even be beneficial [16]. It also suggests that hospital admissions maybe a symptom of the apparent medicalisation of death, such that even when facing death, some patients or their family wish to be in hospital so as to receive life-sustaining
treatment or because they feel the care is better there [10, 183]. It also considers that in the current situation, “nurses and GPs actually might have limited ability to prevent such end of life admissions” ([16] p.946).

However, whilst this literature is helpful for understanding why some admissions do occur, its explanations are also primarily drawn from the context of policy and its exploration of the rhetoric of end-of-life care is thus limited. The promoted ideals of planning and the desirability of home for example are rarely questioned (with notable exceptions, e.g. [63, 183]). Limited space is given to the potential role of wider societal trends for understanding these admissions, such as why participants in their research typically started from an assumption that hospital was not a ‘good’ place to die. Therefore there is much scope for bringing these issues under sociological scrutiny. In order to complete my understanding of the context of hospital admission it is useful though to consider first the resolutions to the hospital admissions problem which have been proposed.

2.3.2 Resolutions to ‘inappropriate’ hospital admissions

The strategies to reduce end-of-life admissions are expansive and provide limited direct learning for understanding admissions but provide useful insight into the ‘problem’ of hospital admissions.

The EOLCS echoes many contemporary policy documents when it sought to reduce hospital admissions by generally improving end-of-life care. Particular solutions included; greater use of advance care planning and a focus on preferences for place of death; increased support in the community: and improved communication between healthcare professionals [1]. These ‘solutions’ expose critical differences to how home and hospital are viewed as places of death by demonstrating that there are recognised problems in dying in hospital and dying at home. Advance care planning suggests that a home has to be prepared and modified before it becomes a suitable place of death, requiring specialist equipment and people. The call for greater community support in the EOLCS suggests that existing provision was unsatisfactory for patients being cared for at home. Similarly, the attempts to improve communication between healthcare settings and staff suggests that patients are vulnerable to receiving disjointed care wherever they are being cared for. Awareness of these widespread problems challenges the perception of home and hospital as dichotomous places of death; one desirable, the other not. This in turn gives greater space for exploring what in practice home and hospital may offer.
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patients at the end-of-life outside of the narrow understanding of place of death often depicted in policy.

The problems of home are rarely explicitly acknowledged in policy (for exceptions: see section 1.3.10): even when recognised they are not construed as challenging its desirability as a place of death. The opposite is true of hospital. This seems in part because the problems of home are framed as general issues to do with community provision and are not tied specifically to what is meant by home. This therefore allows the ideal of dying at home to be preserved. By comparison, the problems with hospital as a place of death are attributed to the hospital as an institution, whether they are to do with the hospital environment (the noisiness and lack of privacy, for example), or the hospital care focus (specifically the emphasis on curative treatment). It is perhaps inevitable then that hospital as a place of care is constructed as incompatible with a ‘good death’, particularly in early end-of-life care policy documentation.

2.4 Always ‘inappropriate’?

The negative construction of hospital admissions is however not total. Within policy, the pejorative descriptors of admissions imply that the converse may sometimes be true; admissions which are appropriate, or not avoidable, or even desirable. This accords with empirical research on end-of-life admissions.

Quantitative research finds that the majority of patients (between 67-87%) reviewed who either died in hospital or who had palliative care needs were appropriately located in hospital, with between 6.7%- 24% of admissions considered avoidable or inappropriate [183-186]. These conclusions are also found in qualitative studies, which show that healthcare professionals do not view all admissions as ‘avoidable’ and demonstrate that, like general ‘inappropriate’ decisions, they depend on the availability of alternative care and patient preferences [10, 16]. It is unsurprising therefore that defining admissions as appropriate or not has been found difficult for healthcare professionals to do [10, 16].

Across this research, hospital is recognised to be appropriate in the following situations: where the home environment is found to be unsuitable (including family carers capability); where there has been inadequate communication, whether between healthcare professionals or to the patient; or there are insufficient resources in the community [10, 13, 16, 187]. This research is valuable for stating that hospital need not be considered a poor place of death. However, the reasons for admissions are still situated within this context, occurring because of some deficiency in care or
environment. This is problematic because failure of some aspect of end-of-life care is implicit in the utilisation of the term ‘inappropriate’ admissions, and therefore implies that the research may not have addressed concerns outside of the immediate remit of end-of-life care.

2.4.1.1 Why none of these resolutions are enough

The reasons or justifications for admissions given above are common across similar cultural contexts (the above studies were conducted in the UK [184, 186], Belgium [16], the Netherlands [185] and New Zealand [10]) and could suggest that ‘inappropriate’ hospital admissions are already understood. However, as identified above, the justifications are not wholly satisfying. Whilst this research challenges some of the assumptions of hospital admissions particularly around place, other variation, such as the differences in care needs at the end-of-life between patients, or the suggested measures to improve care and thus reduce admissions, are infrequently explored. The themes are useful for identifying general trends in admissions to hospital, but they explain little about the individual circumstances that lead to a patient being admitted, or conversely, how the ‘problems’ interrelate and the wider context that they exist within.

3 Conclusion

Hospitals in Britain have existed in a variety of different forms, and across all death has been a ubiquitous feature. The survey in this chapter shows that the means of dealing with death in these institutions has often not been optimal - a characteristic that still pervades contemporary NHS hospitals. In recent conceptions, the dying patient has been particularly marginalised. Whilst the formation of the NHS ensured the inclusion of dying patients in hospital, the growth of palliative care and its location in the hospice reinstated hospital as a site not appropriate for dying patients.

The policy ambition to have fewer ‘inappropriate’ end-of-life hospital admissions can thus be regarded as a contemporary manifestation of a long trend. Whilst reducing admissions is justified primarily in terms of patient choice, it also helps to achieve the wider aim of having fewer patients cared for in institutions, and is hoped to generate funds to finance community support. However, the evidence presented in this and the previous chapter shows that these claims, and the demographic changes which frame admissions and are used as an impetus for change, are not as straightforward as suggested. In turn, the phrase ‘inappropriate’ has been found to be highly subjective.
This indicates scope for sociological review, and, given the national focus of much of the evidence, for a small-scale, qualitative research study to understand the practical reality of how patients come to be dying in hospital. There is currently little consideration in the available literature on the practical role of healthcare professionals and family or the structural constraints outside of end-of-life care that must surely contribute to our conception of hospital as ‘inappropriate’ when dying.

This chapter has also raised a number of specific sociological issues. I address these in chapter 8 with a variety of sociological themes in addition to the empirical findings from chapters 5-7. To understand the persistence of hospital as contrary to ‘good’ end-of-life care, I use Giddens [188] argument of sedimented practices. End-of-life care policy is characterised by a focus on linear planning and to explore this further I consider the work of Whorf [189] and Bernstein [190] and how terminology can determine or contextualise action, Burns and Stalker [191] and their conception of organic and mechanical organisation, and Etzioni [192] thesis on organisational goals and the means to achieve them.
Chapter 4
The ACE Study: methodological and theoretical reflections

There is a significant rhetoric about hospital admissions, in which admissions are presented as objective phenomena which can be dichotomised as appropriate and inappropriate. However, over the course of the previous chapter it was clear that this perspective overlooks a diversity of influences which have contributed to the construction of ‘inappropriate’ admissions, in turn hindering our understanding of how and why they occur. To answer these questions I will use data from the Admissions Close to the End-of-life (ACE) study. Before I can do so, I need to consider the theoretical and methodological issues of using these data, and I explore these throughout this chapter.

In section one I begin by outlining the study; first by reviewing its history and aims, and second by reflectively considering the study design, including a review of patient criteria and the research process. I consider next the interviews that were conducted, including the interview process and my role as an interviewer. I conclude this section by reviewing relevant issues to the study.

In section two I discuss how I analysed this dataset. After mapping out my PhD process, I consider the complexity of using a (personally collected) ‘secondary’ dataset, and explore the theoretical tensions of using retrospective interviews. Giddens [188] structuration theory provides a framework to resolve these strains, whilst a selection of literature in the interactionist theme gives solutions to issues of accuracy. Next I concentrate on the analysis of this dataset, considering the methodological approach and the practical steps I took, before concluding with a description of my synthesis and writing process.

1 The hospital Admissions Close to the End of life (ACE) study
1.1 Study aims
The ACE study is an in-depth, qualitative study of the hospital admissions of nine case-patients. The study predates my PhD and I used data I collected from it, but it is a distinct study. It aims to “understand the decision processes that result in a patient being
admitted to hospital where they die soon afterwards. It is designed to explore how decisions resulting in inpatient admissions close to death are made and valued from the perspective of the decision-makers themselves, and to consider the implications for policy and practice” [20]. It was conceived as a three-part study, of which one phase was completed; an interview study, based at two hospital sites. An extended discussion of the study design follows below.

1.1.1 The history of ACE

The ACE study was conceived in 2008 by Dr Barclay. As a member of the national End of Life Care Programme working group (for further information on this see chapter 3, section 1.1.2) it had become apparent that inappropriate admissions were to be a key policy focus, and there had been little academic research about them. The study design was developed by Dr Barclay together with Dr Morris and Dr Momen, and with advice and support from the ACE study Patient and Carer Group who had experience of end-of-life care, and a stakeholder group of healthcare professionals. After the team secured ethical approval for the study (which had been a protracted process; See section 1.7.1) Dr Momen left the study and I joined as a research assistant. I organised the site approvals at each of the 10 NHS trusts that were involved in the research (including community, ambulance and out-of-hours services), and started the interview study at Meadowbridge hospital in the autumn of 2012, following the departure of Dr Morris. In January 2013, Dr Walsh joined the team to set up and conduct research at a second hospital site, whilst I continued to conduct interviews at Meadowbridge and organise and liaise with all study sites. Following the completion of data collection at the second site and the end of funding, Dr Walsh left the study in summer 2013. After a successful funding application, I continued in the study as a dual research assistant/PhD student, with the analysis of the ACE dataset the initial focus of my PhD.

1.2 The Use of ACE

The design and approach of ACE evolved to meet my research needs and interests. The main focus of ACE became the interview study I had conducted at Meadowbridge; the study analysis changed from a focus on understanding behaviour with a theoretical focus on social marketing behaviour [20] and analysis using a framework approach [193], to the social context of admissions for which I undertook a more in-depth analysis. The ACE study has afforded me a valuable insight into hospital admissions at the end of life from the perspective of those involved in making admissions happen, and, through its
retrospective case-study design, has encouraged a focus on the process of admissions rather than their outcome [194].

1.3 The design of the ACE study

The ACE study focused on patients who had died within three days of admission to Meadowbridge hospital. For each of the patients (henceforth described as ‘case-patients’), I identified and conducted interviews with up to five members of staff from both the community and hospital settings who had been involved in their admission, and where possible also with the patients’ next of kin (collectively described as a ‘case’). In the following sections I explore in detail various aspects of the design that are relevant to the nature of the empirical data that was collected.

1.3.1 Case study

The study design can be considered an embedded multiple unit of analysis, single case study ([195] p.53-60). The case design was chosen to encourage interviewees to focus on their involvement with a specific patient, rather than to talk more generally about admissions.

The multiple accounts of a patient’s admission considered collectively were helpful because they could provide a comprehensive description of a patient’s admission even with missing perspectives. Within cases, others’ accounts helped cover ‘gaps’ in the story of the patients’ admissions, because participants typically referred to what had happened to the patient prior to, or post, their involvement. Across cases, perspectives could be used to identify potential aspects of admissions that were specific to a role, compensating for missing voices within a case. Both were important because of the novelty of the design. It was not known at the time of design how successful recruitment would be, and the case approach meant that collected data could be maximised even with limited interview uptake.

1.3.2 Retrospective

The study uses a retrospective design because of the difficulty of identifying end-of-life care patients prospectively. This is in part because prognosticating death is often inaccurate, even close to death, and because communicating end-of-life decisions is difficult, especially in hospital (e.g. [196]). Furthermore, some conditions are not always recognised to be terminal (such as Chronic Obstructive Pulmonary Disease (COPD)) so that patients with these conditions may not be formally considered to be ‘end-of-life’ even
when they are very close to death. Whilst patient notes could potentially have been used to prospectively identify if a patient was dying through proxy indicators such as treatment and care decisions, I did not have permission to do so within the ethics approval in place for the study.

1.3.3 Meadowbridge hospital and the surrounding area

Meadowbridge is a real hospital, although its name is fictional. It is located in a small city (approximate population of 100,000) and serves a geographically diverse area, much of it rural. Its catchment area extends beyond the county, in part because Meadowbridge is located near the county border with great variation in deprivation levels. The immediate area around the hospital is however relatively affluent by levels of economic deprivation and health variables; with a high employment rate and a majority of residents describing their health as ‘Very Good’ or ‘Good’ [197].

The Clinical Commissioning Group that covers Meadowbridge performs well in terms of the currently accepted end-of-life care quality indicators. It is below the national average for the number of deaths in hospital, and correspondingly above average for deaths at home, in a care home and other places (and with no significant difference for deaths in hospice)[4]. It broadly matches the England average for percentage of deaths from an underlying cause of cancer, circulatory, respiratory, or other causes [4]. Meadowbridge has a hospital-based specialist palliative care team: community palliative care for the area is provided by a nearby hospice that at the time of data collection offered in-patient care, day therapy and a hospice-at-home service[38].

1.4 Patients

The ACE study focussed on patients who had died within 3 days of admission, were aged over 65 and had either cancer, dementia or COPD recorded on their Medical Certificate for Cause of Death (MCCD).[39] I explore these criteria in detail next.

1.4.1 Three days

The three-day threshold was decided on by hospital death trends and practicalities of securing interviews. Within the county that Meadowbridge was in, 32% of hospital deaths occurred within three days in 2014/5, as Figure 14 shows.[40] This matches national trends (for further discussion see chapter 3, section 1.4.3). Focusing on patients who were admitted and died within three days therefore meant that the research could capture the ‘peak’ in admissions ending in death, and matched policy concern with short
admissions (chapter 1, section 2.2). Exploring the admission of patients who had been at Meadowbridge for a longer period prior to death was thought by the study team to be difficult to achieve retrospectively because of difficulties identifying staff and facilitating recall [20].

Figure 14 Deaths in hospital by length of stay and age group in Meadowbridge county

1.4.2 Age

The focus on patients over the age of 65 was to encourage a study focus on ‘typical’ hospital admissions which end in death. As outlined previously (chapter 3, section 1.4.3), most deaths in the UK occur in this age-group, and current trends suggest will continue to do so. Children were excluded because their end-of-life provision is often distinct to adult care, reflecting differences in care priorities and common diseases treated [1].

1.4.3 The disease focus

The three disease categories allowed the opportunity to explore potential differences in care by disease. Each is a prevalent example of a particular trajectory of decline to death and whilst contested [199] are recognised in the EOLCS as a contributing factor to the design of end-of-life care pathways, and thus suggest that they may have an effect on hospital admissions and place of death [1]. The relatively steady decline and clear terminal phase of cancer, for example, is thought to be more predictable than for patients with organ failure such as COPD where there are far greater fluctuations in health, and more recognisable as ‘end of life’ than for those with dementia whose decline is more gradual [200]. Thus it is presumed that cancer patients are less likely to die in
hospital than patients with dementia or COPD, in part because the predictability gives greater opportunity for planning end-of-life care [200]. To provide context to the empirical data, next I provide a short description of each of the diseases including prevalence, epidemiology, diagnosis and treatment.

1.4.3.1 Cancer

Cancer is a condition where cells in the body reproduce and grow uncontrollably, destroying healthy tissue [201]. In England and Wales cancer was the most common cause of death (28%) in 2015 [202], with the most prevalent types -breast, prostrate, lung and colorectal cancer- together accounting for more than half of all malignant cancer registrations in 2014 [203]. The risk of developing a cancer is in part attributed to lifestyle and environmental factors [204], and reflecting these, incidence is highly patterned by socio-economic deprivation, such that the most deprived groups have the highest prevalence rate of cancer [205]. Age is also relevant, with over half of all cancers registered in 2014 of people aged over 70, and prevalence increasing with age [203].

Typical treatment for cancer includes one or a combination of surgery, chemotherapy and radiotherapy, with treatment dependent on the type and extent of the cancer, as well as other factors [206, 207]. The prognosis of the condition similarly depends on the type of cancer the patient has and when it was diagnosed, since early treatment is correlated with a greater chance of survival [208].

1.4.3.2 Dementia

Dementia is a syndrome which encompasses conditions that lead to a progressive disturbance in cognitive function such as memory, thinking, language, and comprehension caused by changes to the brain. These symptoms are often accompanied by changes in social behaviour and emotional control [209]. Dementia is primarily an older persons' condition and in the UK it is estimated that 1 in 14 people over 65 have dementia [210]. As with the concern with ageing populations, many high income countries are said to be experiencing an ‘dementia-epidemic’ (e.g. [211]) although recent work estimating prevalence in the UK [212] and western Europe [213] suggests that dementia incidence in these countries are stabilising.

Very limited drug treatments are available to reduce the inexorable disease progression [214]. Official advice for patients therefore focuses on care planning, psychological
interventions, occupational therapy and practical help to facilitate independent living in combination with social programmes [215, 216].

1.4.3.3 COPD

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung condition which causes airways to become obstructed, affecting patients’ ability to breathe easily [217]. It is a prevalent cause of death in high-income countries [218] and nearly 2% of England’s population in 2014 had a COPD diagnosis, although this is thought to be an under-estimate of actual prevalence [219].

COPD is associated with smoking, with the majority of COPD deaths in high-income countries attributed to tobacco. COPD can also occur due to exposure to environmental pollutants, genetic factors and prior infections, and often a combination of these factors [220]. Greater exposure to these risk factors is thought to explain the association between COPD, poverty and low social status, with people typically diagnosed in the 50s and 60s [221, 222].

COPD is characterised by acute ‘exacerbations’ (rapid and sudden worsening of symptoms) which are often due to infection, largely reversible and may require acute hospital treatment [217]. Long-term maintenance treatment typically involves inhalers and oral medication and smoking cessation practices where relevant. Patients frequently also receive oxygen therapy delivered through a nasal tube or mask, often for significant periods of the day. Surgical treatment is possible but limited, and is only offered to a minority of patients [223]. Pulmonary rehabilitation improves lung function, confidence, mobility and awareness about the condition [224].

1.5 Data collection

1.5.1 Case-patients

Potential case-patients were identified using the study criteria by the Meadowbridge bereavement team, whose office is the initial depository for the hospital notes of recently deceased patients. They excluded patients if their death had been referred to a coroner, or the patient was not resident in either the hospital county or an adjoining one. I then selected patients for inclusion, where possible purposively sampling in order to achieve a variety of cases by previous place of care, gender, the three disease categories of cause of death and age. However there was often little choice and since I was reluctant to refuse
eligible cases due to a finite data-collection period, the variation in case-patients by inclusion criteria is limited.

Table 2 Case patient characteristics

<table>
<thead>
<tr>
<th>Case-patient</th>
<th>Age</th>
<th>Case-condition</th>
<th>Previous place of care</th>
<th>Time of admission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td></td>
<td>Home</td>
<td></td>
<td>Week day, daytime</td>
</tr>
<tr>
<td>Cancer</td>
<td></td>
<td>Home</td>
<td></td>
<td>Week day, evening*</td>
</tr>
<tr>
<td>COPD</td>
<td></td>
<td>Home</td>
<td></td>
<td>Weekend*</td>
</tr>
<tr>
<td>COPD</td>
<td></td>
<td>Home</td>
<td></td>
<td>Weekday, daytime</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>Home</td>
<td></td>
<td>Weekend*</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>Home</td>
<td></td>
<td>Weekend*</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>Residential Home</td>
<td></td>
<td>Week day, daytime</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>Residential Home</td>
<td></td>
<td>Week day, early morning*</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>Residential Home</td>
<td></td>
<td>Weekend*</td>
</tr>
</tbody>
</table>

One case-patient was aged between 60-69 years, two were aged between 70-79 years, five were aged between 80-89 years and one was aged between 90-99 years.

* These patients were admitted out-of-hours

Table 2 outlines the nine case-patients by the inclusion diagnosis and previous place of care, and Box 3 provides a more in-depth history of each patient. The sample includes more women (n=7) than men (n=2), in contrast to national trends where broadly equal proportions of each gender die in hospital, but reflecting the limited pool of participants who fitted the inclusion criteria [225]. Of the three disease categories of interest, the majority (n=5) had dementia. I had incorrectly anticipated difficulty in identifying these patients, as under-reporting of dementia on death certificates is a recognised problem (e.g. [226-228]) and had therefore particularly sought them out. Care home admissions are over-represented (3 of 9) as nationally 22% (2 of 9 in my sample) of deaths occur in care homes, but this may reflect local trends, as within the Meadowbridge county the proportion of care-home deaths are higher than the national average [4].
Box 3 Case-patient summaries

Box 3 provided brief summaries of the case-patients care and medical history in the year prior to their final hospital admission. This box has been removed for anonymity reasons.
1.5.2 Participants

I reviewed the hospital notes of the final admission of each case-patient to identify healthcare professionals from both the acute and community settings who had been involved in the admission. Snowball sampling (e.g. [229]) was also used during interviews, where relevant, to gather further relevant participants not mentioned in the notes. The aim was to conduct interviews with up to five healthcare professionals, with representation from both community and hospital settings where possible. Figure 15 outlines the number of interviews per case by interviewee role, and demonstrates the difficulty of achieving this, with only two cases involving five (or more) interviews. In the next section I explain why this was difficult to achieve through a discussion of the recruitment strategy.
Recruitment strategy

Healthcare staff identified in the paper records as having been involved in the admission were contacted as soon as possible after the death, primarily via email. Overall, just less than half (48%) of all potential healthcare staff participants were interviewed, with a third not replying (38%), and the rest either declining (5%) or withdrawing (9%) after contact and before the interview took place. Participants declined because they had previously been interviewed or because they thought someone else would be able to give a better account. I classified a participant as withdrawing if they had responded positively to my initial contact but then did not reply to requests for an interview.

Next-of-kin were contacted three to six months after the patients’ death. This time period is recognised to be an appropriate compromise between minimising carer distress, and facilitating recall [230]. Next-of-kin were contacted by the hospital bereavement service on my behalf. Next-of-kin, or a nominated alternative, could then contact me to accept or decline the interview. Relying on letter-communication probably reduced the response rate (4 of 9 did not reply) but was the only approach permitted by the research ethics committee.

There were staff representatives from hospital in every case, but not for ambulance and community settings, as shown in Figure 15. This may be because it was easier to identify and contact hospital staff. The hospital bereavement care team helped me to decode unintelligible signatures of hand-written records and I used the Meadowbridge email system to acquire contact details and verify names (supplemented by internet searches...
I recruited ambulance staff with help from the local ambulance service, who decoded call signs recorded in the hospital notes to identify ambulance staff. In several of the cases patients were taken to hospital by private ambulances and these staff were not interviewed. Permission had not been sought from these private companies prior to the start of the research because it was not anticipated that they would be involved; whilst this was later granted by some companies, I received it too late to recruit staff.

Contact information for GPs was often included in hospital records so it was easy to contact the GP practice, although more difficult to negotiate access from practice receptions to contact staff directly. In three cases I did not initially have permission to contact the GP because they were located in a different county to Meadowbridge. Whilst I eventually secured this permission, the delay seems likely to have affected recruitment. All but one of the community staff were GPs; next I discuss the absence of nurses.

### Table 3 Study Participants

<table>
<thead>
<tr>
<th>Participant role</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>5</td>
</tr>
<tr>
<td>Community nurse specialist</td>
<td>1</td>
</tr>
<tr>
<td>A&amp;E Consultant</td>
<td>3</td>
</tr>
<tr>
<td>A&amp;E Registrar</td>
<td>3</td>
</tr>
<tr>
<td>GP Trainee</td>
<td>1</td>
</tr>
<tr>
<td>Ward Consultant</td>
<td>4</td>
</tr>
<tr>
<td>Ward Registrar</td>
<td>5</td>
</tr>
<tr>
<td>Ward Junior Doctor</td>
<td>2</td>
</tr>
<tr>
<td>Pastoral worker</td>
<td>1</td>
</tr>
<tr>
<td>Paramedic</td>
<td>2</td>
</tr>
<tr>
<td>Student paramedic</td>
<td>3</td>
</tr>
<tr>
<td>Emergency care assistant</td>
<td>1</td>
</tr>
<tr>
<td>Son</td>
<td>2</td>
</tr>
<tr>
<td>Wife</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>33</strong></td>
</tr>
</tbody>
</table>

### 1.5.2.2 Missing voices

The ACE dataset for the Meadowbridge area comprises 34 interviews but largely lacks the perspectives of nurses and entirely lacks care home staff perspectives (see table 3).

Only one nurse is included in the study, despite adaptations to recruitment processes. A first problem was that ward nurses were unlikely to be able to access emails on shift, and I therefore delivered recruitment letters to wards. Second, community nurses were often not recorded in hospital notes, so I asked GP interviewees for their contact details if it seemed like they had been significantly involved in the patients’ care. Third, nursing staff seemed hesitant to take part, perhaps out of concern that they would be asked to discuss poor care, and I therefore met with senior hospital nursing staff to promote the research. The relative absence of nurses in the study is an important limitation.
Entirely missing are the perspectives of care home staff. None of the three care homes I contacted agreed for their staff to be involved in the study, despite approaches by email, telephone calls and letters, and where requested, attempts to gain permission from more senior managers. In retrospect, it is likely that further amendments to the recruitment approach would have been necessary to interview care home staff [231]. The political climate during the data-collection period was also relevant. In the autumn of 2012 there was media attention about poor care in residential homes (e.g. [232]), including descriptions of a Care Quality Commission report that found that care provision in residential homes did not always meet national standards [11]. In the months prior to the study starting, there were high-profile arrests of care staff working at Winterbourne View, a private residential hospital for people with learning difficulties[233]. In this context, it is perhaps unsurprising that care-home managers did not want their staff to take part in an interview about end-of-life admissions, which, like care home provision, are often pejoratively described. As with nursing staff, the lack of care-home staff perspectives is a significant potential limitation.

1.6 Interviews

The interviews were semi-structured; I had topics I wanted to cover with interviewees, but the order that I covered these, and the way I broached them changed with each interview according to the way the conversation unfolded [234]. A copy of the interview schedules can be found in Appendix 5. The interviews with hospital staff considered their involvement in the admission, and sought their opinion on hospital admissions for patients close to the end of life. The healthcare staff interviews predominately occurred in their workplace during the working day, in accordance with their preferences. Interviews were relatively short (a mean of 22 minutes, excluding consent process) to facilitate uptake but with sufficient time to gain an overview of the patients’ admission. The interviews typically occurred within three weeks of the patient’s death, with an association between a longer gap and the seniority of the staff member, with the delay often due to intermediary contact with a secretary or receptionist. However, I noticed no obvious difference in interviewees’ recall of the patient or the admission, perhaps because these staff were more likely to mention that they had read patient notes (or brought them to the interview) than more junior staff. (For further discussion on recall see chapter 4, section 2.3.1.1). All participants were given a £25 honorarium, either as shopping vouchers or a charity donation at the participants’ request, which unsurprisingly seemed more of an incentive to those in low-paid positions.
Interviews with next-of-kin were longer, lasting an average of two hours including taking consent, and all occurred at their homes. The interviews covered the patient’s admission and the preceding months. Whilst I used an interview schedule, they were more loosely structured than the staff interviews and where relevant I encouraged digressions to allow the participant opportunity to recover their composure if they had become upset. The most noteworthy difference between the interviews was the way the patient was reconstructed. Staff interviews typically included few personal details about the patient, sometimes not even their name, and perhaps because they tended to occur in the workplace, had a more professional, impersonal context [235]. Next-of-kin interviewees by contrast conjured up the day-to-day life of the patient, and as a consequence were far more emotionally draining to conduct, and later analyse.

1.6.1 Telephone interviews

Two of the healthcare staff interviews were conducted over the telephone at the interviewee’s request. As well as convenience, telephoning seemed to provide a welcome additional layer of confidentiality. One of the telephone interviewees was reflective about their involvement in what they perceived to be an inappropriate admission of a case-patient, and I perceived their candour was partly because they could not see me. This correlates with Sturges and Hanrahan [236] who found some interviewees chose to be interviewed by telephone because of the belief it gave greater privacy, and who similarly found no important differences in the interview output to those conducted face-to-face [236]. As an interviewer however, I disliked having to interrupt interviewee speech with oral affirmations to demonstrate I was listening and it was necessary to pay greater attention to speech pattern to compensate for the absence of visual social cues.

1.6.2 Recording

In all but one of the interviews I audio recorded the discussion using a small hand-held recorder, with the addition of an ear piece when recording telephone interviews. I accidentally did not record the second interview I conducted. Despite my subsequent wariness with the recorder, most participants seemed unconcerned by it, although next-of-kin and ambulance staff were more hesitant. To reduce its possible distraction, I sought to place the recorder out of interviewees’ eye-line, although it was not concealed because interviewees had consented to being audio-recorded.
1.6.3 After the interview

After I had closed the interview, there was often distinct change in the atmosphere of the encounter, whether to a return to work – I recorded in field notes how one participant “at end of interview [interviewee] just turned to emails (v much let myself out)” – or ‘socialising’[237]. Whilst the former response was disconcerting, the latter led to ethical qualms, because the interviewee would often give further comments and it was unclear whether they considered these to be ‘off-record’ or ones they were happy to be considered part of the interview. I recorded these comments in field notes because I perceived what they were telling me was within the context of the interview, but thought it inappropriate to turn the recorder back on without their explicit consent, as some have suggested (e.g.[237]). In later interviews I avoided this difficulty by leaving the recorder running after I had officially ‘ended’ the interview and had started discussing their expenses. Following each interview I wrote a short reflection on it, including comments on what was said and memory prompts, including notes on the location and conduct of the interviewee.

1.6.4 Myself as interviewer

During interviewing I was often mistaken for an undergraduate student, suggesting my attempts to present myself as a researcher were unsuccessful [238]. However, being just ‘a girl from the University’ [239] brought unexpected benefits beyond concern about how I would get home after the interview. Participants expressed their desire to help me as someone ‘starting out’, and my apparent young age appeared to reassure next-of-kin interviewees unfamiliar with being interviewed. My perceived vulnerability was useful for defusing some of the threat of discussing the potentially challenging topic of inappropriate admissions than someone thought to be more experienced ((240)p.1184). Participants frequently gave opinions (not always favourable) about other professions involved in end-of-life care and I think my role as a medical ‘outsider’ was beneficial here, as I had no known affiliation with any profession [239].

At times though, my age (perhaps in combination with my gender) was a shortcoming, particularly with older senior interviewees. I experienced on a few occasions what I felt were ‘public accounts’, whereby interviewees spoke as if explaining to an audience on a ward round, “giving fairly full answers but speaking almost as if […] dictating” ([240] p.1184), or ‘just talk’ that was fluent but subtly skirted the topics I asked about ([241] p.21). Inadvertently, however, I seemed to excel at the naïve researcher role that is often
recommended in qualitative interviewing in order to probe interviewees about familiar topics [242]. I was new to health research, with no clinical background, and really could not understand why a patient could not be sent home from A&E, or why an operation could not be performed on a dying patient. Sometimes the balance between “expert and ignoramus” that McDowell recommends for elite interview (cited in [243] p.14) tipped too far in the latter direction, and my non-clinical background became a disadvantage. I was quizzed on my educational background, seemingly to check my suitability, or trustworthiness for conducting sensitive research [242]. Where I perceived this, I would not ask for non-technical explanations for medical conditions. This pretence that I understood terms meant interviewees seemed to align with me more as a co-conspirators in ‘this difficult situation’[239].

My interview approach changed throughout the series of interviews. On occasion this was an active variation, as I trialled a more conversational approach rather than subscribing wholly to the idea of interviewer neutrality, but primarily the changes reflected my increasing experience as an interviewer and familiarity to the interview schedule. This change is difficult to identify in the transcripts, demonstrating Rapley’s [244] argument that interview talk instead depends on the context of the interview and the interaction between interviewee and interviewer.

1.6.5 Transcription

The interviews were transcribed verbatim by a professional company. Recognising that transcripts are “are impoverished, decontextualized renderings of live interview conversations” ([245] p.204) these transcripts are particularly underprivileged because they exclude much of the speech pattern. Whilst large pauses and laughs are accounted for, intonations, filler ‘ums’ and ‘ers’ and vernacular expressions are not [246]. The transcription fitted the original scope of the ACE study and meant a time-consuming process was completed quickly and cost-effectively. The linguistic information is of greater contextual importance rather than analytic, since I did not undertake a discourse analysis. As the interviewer and analyst, I compensated for some of this loss through recollections, field notes, and by listening to the interview transcripts.
1.7 Ethical issues

1.7.1 Approvals

The ACE study was approved by the Hertfordshire Research Ethics Committee (England) (#11/EE/0491). The study also received subsequent approval from what was the National Information Governance Board (NIGB) (ECC 1–05 (g)/2012), and I renewed both approvals during the course of this research. The need for two forms of approval was necessary to look at the hospital records of deceased patients, for whom we clearly could not obtain patient consent and for whom proxy consent gained via next-of-kin was neither legally permissible nor considered ethically appropriate by either the research team or NIGB.

1.7.2 Consent

All participants who agreed to take part were sent study information and prior to the start of any interview I established that participants still wished to take part in the study and confirmed this by asking them to sign an informed consent form (see Appendix 6). All participants agreed, with verbal consent gained for the two telephone interviews followed after the interview by signed paper copies returned by post. There were two instances where I felt unsure of this process. The first was with a next-of-kin whose grief and loneliness I was concerned I was taking advantage of. However, they appeared to understand the consent process and spoke lucidly in the interview about their next-of-kin; the vulnerability of bereaved relatives does not mean that they should necessarily be excluded from research [247]. The second was a GP, who part-way through the interview made an unfavourable comment about a different profession and stated that if the conversation was being recorded they would be in trouble. However, since we had discussed the recording prior to the interview as they helped me find a suitable place for the recorder, I decided it was more likely to be a figure of speech and continued with the interview.

1.7.3 Anonymity

In line with these approvals and the conditions of informed consent, I have sought to maintain the anonymity of the participants and case-patients. It is hoped that the measures outlined below in addition to the time between the case-patients’ deaths and the writing of this thesis will reduce the likelihood of deductive disclosure, but this remains a study risk [248].
All case-patients and participants have been given pseudonyms which match their gender and cultural heritage as far as was apparent from their real names. The role of participants has been generalised in order to encourage anonymity, as Table 4 outlines below, with increasingly ambiguous labels for their role in columns to the right of the page. The first column is based on their own description of their role, the second a pseudonym title where levels of seniority (where relevant) are collapsed into a general descriptive role, the third column groups staff by occupation and location, and the fourth by interview categories. In the following chapters, participant references are the most ambiguous label appropriate for the context. The interview transcripts were amended to remove references to other personal data. To recreate the familiarity found within the original accounts, these references were replaced with pseudonyms or, where this was less pertinent, prosaic descriptions. All amendments to the transcript text were denoted by square brackets, and these are also used in the quotations in the chapter.

<table>
<thead>
<tr>
<th>Participant role</th>
<th>Pseudonym role</th>
<th>Group role</th>
<th>Category role</th>
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</thead>
<tbody>
<tr>
<td>GP</td>
<td>GP</td>
<td>Community staff</td>
<td></td>
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<tr>
<td>Community nurse specialist*</td>
<td>Community nurse specialist</td>
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<td></td>
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<tr>
<td>A&amp;E Consultant</td>
<td>A&amp;E doctor</td>
<td>Hospital staff</td>
<td>Healthcare staff</td>
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<td>A&amp;E Registrar</td>
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<tr>
<td>GP Trainee*</td>
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<td>Ward Consultant</td>
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<td>Ward Registrar</td>
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<td>Ward Junior Doctor</td>
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<td>Pastoral worker*</td>
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<tr>
<td>Paramedic</td>
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<td>Student paramedic</td>
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<td>Emergency care assistant</td>
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<td>Son</td>
<td>Next-of-kin</td>
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<td>Wife</td>
<td>Next-of-kin</td>
<td>Next-of-kin</td>
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</tr>
</tbody>
</table>

* on A&E rotation when caring for patient  * Imprecise participant role title to encourage anonymity

1.7.4 Participant codes

Each interviewee was given a unique code which was used to organise transcripts and audio files, comprised of letters and numbers attributed to the hospital sites, patient-cases and the order in which interviews were conducted. In the empirical chapters that follow, these codes have been replaced by interview numbers to help preserve patient anonymity (see Table 7). Whilst these necessarily link interviewees to case-patients, other references have been removed.
1.7.5 End-of-life memories

The subject matter of my research was, and continues to be, sometimes difficult, as previously noted. It was not just exploring the patients’ deaths and witnessing the grief of their family, it is the reminders it prompts of other deaths I have experienced prior to and during the research process, and awareness of the mortality of older adults I care about. Peer supervision, and the support of colleagues within the Department’s Palliative and End-of-life Care Group have been helpful in this regard. Equally helpful was the positive way in which participants regarded the life and care of the case-patients. Healthcare staff expressed sincere concern for the welfare of the patients, and in this way the interviews were very positive, regardless of the often sad situations they described. Similarly, the warmth with which next-of-kin described their relatives, and the efforts that they had gone to support them made hearing their accounts a privilege. This sadness and positivity was also identified by Kendall, Harris [59] in their study of researching end-of-life issues, and seems to be a hallmark of this type of research.

1.8 Summary

The ACE study uses a novel way to explore end-of-life admissions. Whilst the retrospective design was not straightforward to conduct, it provided an innovative way to understand patients’ journey to hospital and to gain multiple perspectives on why a patient was cared for in hospital. Having now reflected and described the ACE Study and the accompanying dataset, it is appropriate to now explore the analytic process I conducted as part of my PhD research.

2 Analysing the ACE dataset

2.1 Reading

I began my PhD research, the analysis of these interviews, by consulting the sociological literature. I started by reading summaries of the main debates and topics of the discipline, which was essential as I was new to the field of medical sociology. Next, I undertook targeted reading to answer preliminary questions that had arisen from conducting and thinking about the interviews. It was apparent from participant accounts that end-of-life care was far from the straightforward process I had presumed it to be from policy documents. To understand the distance between this and the messy scenarios described by participants, I drew from an eclectic variety of sociological texts, guided by Professor Kelly. A refined product of this reading can be found in chapter 8.
The texts helped developed my ‘sociological imagination’ too[249]. I became more aware of the social contexts in which the participants were working in and the constraints and opportunities this provided. Whilst it could be argued that the reading ‘biased’ my perception of the interviewees’ accounts, the greater awareness it provided me with was fundamental for understanding how and why participants acted as they described. The sociological literature provided me with a lens with which to recognise tensions within staff accounts as they tried to provide appropriate care for end-of-life patients in situations they thought to be inappropriate, and to address the significant symbolic and practical barriers next-of-kin were faced when caring for relatives.

Later, after ‘formal’ analysis had started, I read Giddens [188] and the interactionist literature cited in this chapter. I was struggling with how to unpick participants’ accounts and to understand how to handle inconsistencies or what appeared to be misrepresentations of actions. The texts provided ways to understand and navigate these contradictions, but more importantly, highlighted again the importance of the accounts as a medium to explore how participants made sense of the admissions and the greater context of end-of-life care. Whilst these accounts may have been partial, involving techniques to neutralise negative aspects of their action or those of others, they provide an invaluable insight into why action occurred [250].

Throughout my research, I developed an increasing interest in the developments in end-of-life and palliative care, such that I now see themes relating to it everywhere [249]. I signed up to receive relevant newsletters and journals, attended conferences and consumed main-stream news, and from here gained an awareness of trends, with the preceding policy chapter an outcome of this. I added to this knowledge by talking to the study patients and carer group, who helped me to begin to understand the everyday experience of end-of-life care. Conducting the systematic literature review on preferences for place of death was also helpful. As is apparent from Table 5, this was a lengthy task, and as a consequence I became familiar with the nuances of end-of-life preferences.

Table 5 provides an overview of the research process and the order of events, which demonstrates how tasks frequently spilled into each other and were not discrete events. Writing, for instance, did not formally begin until the summer of 2014, but was informed by notes I had made for conference presentations, emerging ideas and reading. Likewise, I returned to my analysis throughout the writing process to answer emerging questions, and reading occurred throughout the process.
2.2 Theorising interviews

The ACE dataset is a rich resource for understanding hospital admissions. To make the most of the material it was important to address three time-related issues associated with the retrospective design of ACE:

1) interviewees will be unable to give a complete account because they will forget details about the admission
2) interviewees will provide a ‘post-hoc rationalisation’ of the event
3) interviewees will provide an inaccurate account of the event

Giddens [188] structuration theory provides a framework to resolve these problems by demonstrating that individuals are knowledgeable about their activities and the influences that can limit and facilitate their action. In the following section, I begin by briefly outlining structuration theory before addressing each problem in turn.

Table 5 PhD tasks by date

<table>
<thead>
<tr>
<th>Year 1</th>
<th>2013-2014</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
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<th>Mar</th>
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<td></td>
<td></td>
<td>Sociological reading</td>
<td>Preferences review</td>
<td>Policy review</td>
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<td>Preferences review</td>
<td>Policy review</td>
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*=oral presentation ^=poster presentation
2.3 Structuration theory

Structuration theory provides a way to overcome the binary choice often offered in theory and method textbooks of choosing either a theoretical foundation based on the structure of society, or on the interactions of people, by acknowledging both the individual and the society they live in and emphasising their duality. Since hospital admissions, like most social action, occur at an intersection of individual interaction and institutional policy, it seems both necessary and desirable to have a theoretical foundation that overcomes this division.

Structure is defined as both the rules that reproduce society and social practices, and institutions which have persisted across time and space ([188]p.17, 185). Whilst structuring properties such as institutions impose on individuals, facilitating and limiting action, so structures are only created through the interactions across time and space of collective individual agency ([188]p.25-6). Agency is human action, with a particular focus for Giddens on day-to-day activities. Structure and agency continually occur together and are reciprocal. The benefit of structuration theory is not that it recognises both structure and agency, but that it gives space for the interaction of the two (Kelly and Charlton 1995, cited in [251]). The researcher is conceived within structuration theory as an actor in the researched world: not as a passive, anonymous observer nor as the integral piece of the interaction ([188]p.xxx). Those researched are conceived as individuals who are knowledgeable about their life and interactions ([188]p.xxx), and it is this that defuses the three potential problems outlined above. Next I consider in detail how structuration theory helps.

2.3.1 Everyday sociologists

Any social person is an ‘everyday’ sociologist ([188]p.26). We all have account of why we do most things, including an awareness of our own agency, the agency of others and the effect of structural systems ([188]p.26). In undertaking interviews, I expected interviewees to be able to tell me about their involvement in an admission. Their account was likely to involve the processes they went through (their agency), how the work of other healthcare staff helped or hindered (the agency of others) and to include reference to the pressures they felt under, perhaps from government targets or the work culture (structural systems). The accounting that is required in interviews is something we do all the time to ourselves: we constantly reflect on what we do, and how our behaviour fits with that of others([188] p.6). Importantly, we are also likely to theorise about our
activity by linking our understanding of the situation with others ([188]p5-6).
Interviewees frequently gave opinions on why hospital admissions occur in general, as well as why it happened for a particular patient, and this opinion will be an amalgamation of their own experience, discussion with peers and information gained in other ways.

Qualitative interviewing capitalises on this routine practice by using interviewee accounts to understand phenomena, including gaining a perspective on what others do. Account giving is so customary that even research method textbooks, which provide exhaustive advice in conducting an interview, rarely give advice on how to prepare an interviewee. Even in discussions which recognise the interaction of the research interview, the role of the interviewee is largely absent [252]. Instead, advice is focused on how to channel accounts into an appropriate research format, such as giving prompts to expand answers (e.g. [242]).

This is not to say that account giving in the interview setting is not unusual. Whilst social actors may routinely reflect and rationalise their behaviour, accounts are typically only called for if something is ‘specifically puzzling,’ or there is a ‘lapse’ in competency on behalf of the actor ([188] p.6). By asking for these accounts on occasions where neither were perceived by the interviewee to be true, the interviewer is identified either as deviant or an outsider ([238] p.47). Since account-giving is an interaction between speaker and listener, their form will be affected by the role of the listener, so an interview with an ‘outsider’ will shape the account received. Likewise, just as accounts vary according to the audience, so they will vary according to setting: different accounts for example would be given in a law-court compared to a classroom ([188]p.4). The interviewees’ various conceptions of me as an interviewer, and the types of responses I received from them, as outlined in 1.6.4, reflect this.

2.3.1.1 Making it up: Recall

The first problem of conducting interviews on specific events sometime after the event occurred is that details about the case will be forgotten in the intervening period [253]. However, I was surprised that interviewees could recall both the patient and the care they provided for the patient, with relatively little prompting. For example, an A&E doctor, Dr Young who had only cared for a case-patient during their brief stay in A&E, was interviewed 12 days after. We had the following exchange half way through the interview:
Chapter 4

“SH: Yeah. And then, she’d had a fall?

SY: A couple of days earlier she’d had a fall, yeah.

SH: So um.

SY: Sorry, yeah, these details of the case are sort of slowly coming back.

SH: No, this is how they should come back.

SY: They’re in there somewhere.”(16, 6)

Dr Young’s ability to recall events may seem a fortunate occurrence, were it not that similar exchanges happened frequently throughout the interviews. Whilst it was clear that interviewees could not remember every aspect of the patient or the care they provided, overall they provided vivid and detailed accounts of what happened.

Structuration theory helps to explain this. Memory, Giddens conceives, is not just the ‘recall of the past into the present’ because the present is continually occurring, or in Giddens terminology, borrowing from Heidegger, ‘presencing’ [188] p.45). Presencing ties memory to current perception, which in a circular fashion involves, amongst other things, “simultaneously digesting old [information]” ([188] p.46). For example, healthcare staff may be reminded of a patient they saw some time previously when talking to a second patient who has similar symptoms. Through talking to the current patient about their symptoms, the staff member may also recall aspects of the first patient’s condition that were not considered at the time. In this way, “what a person is ‘aware of’ cannot be fixed at a particular point in time” ([188] p.49). Applied to the interviews, we can assume that in a ‘later’ interview (as opposed to an interview soon after the event) interviewees will have more relevant experience to build insight about the event from their work and perhaps from other areas of their life. Therefore, whilst time will be a factor in the account given, a later interview does not necessarily mean that there will be a deterioration of recall, just as an early one does not guarantee a more complete account.

2.3.1.2 Justifying behaviour: post-hoc rationalisation

The second potential problem to be resolved of using the ACE dataset is that interviewees will give an account of their involvement with the patient which is a ‘post-hoc rationalisation’, rather than a description of what they felt happened at the time [20]. This problem presumes two things. Firstly, that an interview would be less likely to involve rationalisation if it occurred soon after the event, since participants would have a greater awareness of their behaviour. I have partly resolved this problem by considering
memory as a fluid repository where things can always be added and taken away, rather than a one-way process where experiences are added once and can be considered again only in reminiscence. It is also helpful to perceive reflection, or memory with introspection, in the same way. Reflection does not occur in discrete occasions, but continuously ([188]p.46). Since reflection is a necessary aspect of rationalisation, an interview at any point after an admission will involve interviewee rationalising.

Secondly, post-hoc rationalisation presumes that it is the interview that causes interviewees to rationalise. But, as identified above, interviewees, as social actors, will continually be reflecting and accounting for behaviour ([188]p.5). This reflection serves to help the actor to understand and make sense of what happened (Somers 1994 in [251]). Rationalising, therefore, is a fundamental aspect of being social and the interview process does not cause it to occur. This does not mean though that the interview will accurately portray the interviewee’s involvement in the admission, and I consider this next.

2.3.1.3 Motivated talk: Interview inaccuracies

The third potential problem of the dataset is that interviewees may lie. It seems plausible that if interviewees were to be dishonest, it would most likely occur when they were describing their reasons for doing (or not doing) something, because motives, unlike actions, are difficult to verify. Actions can be checked against patient notes and other documentation, but why acts are done is less frequently recorded. However, because it is knowledge that is difficult to access from other sources, the ‘why’ or motivation for action is what I needed to know most from interviewees.

Here structuration theory provides little help to resolve the charge of dishonesty. Giddens argues that motives are harder to establish than “grounds for action,” because motives generally exist in the unconscious ([188]p.6). Thinking that is ‘unconscious,’ is rarely accessible, or if it is, is often distorted or repressed ([188]p.4) and, therefore, difficult to articulate. However, this answer is unsatisfying because interviewees did give a motive for their actions if asked. Whether the reason given was the ‘real’ reason is unclear, and could plausibly exist in their unconscious as Giddens suggests. But since we do live in a spoken society, these (potentially inaccurate) reflections are important.

Mills [254] offers a theory of motivation which can resolve this problem, and compliments Giddens’ approach; he emphasises both the account of the individual and the social structures that influence this. His work on motives focuses on those accounts
spoken about in social conduct and given in response to a question about motives or reasons in the context of a conversation (p.905). Mills argues that these motives are social; they can influence, discourage or encourage future acts of the individual or others (p.907). They are socially derived, often learnt from others (p.909) and determined by an individual’s vocabulary. Those who do not use or recognise this vocabulary are unlikely to accept the motive. Thus a GP’s explanation that they facilitated an admission because the patient needed nursing care is unlikely to be accepted by a hospital doctor who thinks dying patients should only be in hospital if they are acutely unwell, and instead may be recognised as an excuse for insufficient planning. As Mills argues, “what is reason for one man is rationalisation for another. The variable is the accepted vocabulary of motives, the ultimates of discourse, of each man’s dominant group about whose opinion he cares” (p.910).

This understanding of motives helps to resolve ‘dishonest’ motives. Since we cannot be inside another’s head, the only alternative if we do not believe a given motive is to ask for another motive. This account too will also be spoken and therefore also social and so the difference between the accounts is only relative (p.909). My view of hospital admissions will be limited by what interviewees know, and what interviewee tell me. I cannot know why an interviewee did a particular act beyond what they understand of their motives and what they disclose. My concern, therefore, is not with assessing what is ‘truthful’ in interview accounts but is instead in understanding the social processes that are revealed by what is said. In conceiving of them in this way, the accounts appreciate because as narratives they provide a way to comprehend the meanings interviewees give to their experiences (p.636). These meanings in turn provide a way to understand the structural influences that affect admissions, and since these are difficult to directly observe, make the accounts particularly valuable (Williams and Popay 1998 in [251]).

2.3.1.4 Accounting for admissions

To understand more about the social context inherent in accounts and interviewee ‘deceit’, Sykes and Matza paper on techniques of neutralisation is helpful. They argue that ‘lies’ in accounts serve a purpose; to neutralise the condemnation of transgressive behaviour, excising it by changing the parameters of the norm, but critically, still allowing the participant to maintain support for the norm that is being challenged. Thus an interviewee concerned about losing their job who facilitated an admission because hospital was a safe option, but excused the admission on the grounds
that hospital was a lesser harm than keeping a patient at home, allows the norm of ‘inappropriate’ admissions to be maintained by ‘appealing to higher loyalties’ in Sykes’ and Matza’s terminology (p.669). This neutralisation in turn may also allow the practice to continue, as this accounting may occur prior to the event [255]. Whilst this claim of causation is contested [256], it fits with Whorf [189] and Bernstein [190] ideas that language and action is tightly entwined.

The role of accounts can be usefully extended further through the work of Scott and Lyman [238], who categorise neutralisation techniques as an example of justifications, whereby the speaker acknowledges an act is ‘wrong’ but argues that in the circumstances given it is acceptable. The purpose of justifications and excuses is to resolve differences between a persons’ action and their explanation when they are considered incongruous. These linguistic devices work in social interaction to smooth over discord and facilitate continued conversation. Scott and Lyman [238] thesis therefore contributes to Mills argument that accounts are inevitably a product of the social encounter, and ‘lies’ are an important methodological device for exploring this.

2.4 Analysis
2.4.1 ‘Secondary’ analysis

In addition to the three problems addressed above, the dataset posed two further challenges as a ‘secondary’ dataset which I needed to resolve before beginning analysis. Whilst completing the interviews myself ameliorated the majority of the disadvantages typically associated with reusing data, I did have to address firstly, the difference between the aims of ACE and those of this research, and secondly, the apparent problem of not being able to conduct my research iteratively [257].

The first problem was not a great concern. Whilst there were differences in aims (section 1.2) as evident in the focus on participant decision-making in the interview schedule, in practice interviewees gave such rich accounts that they inevitably included references to the broader social environment.

The second problem was highlighted in my first year PhD assessment. Iteration is a common feature in qualitative research, particularly that which ascribes to the grounded theory approach, and is typically achieved by interviewing and analysing concurrently. This allows ideas identified from early interview analysis to be explored in subsequent interviews, with the aim of rigorous theory development that is derived from the data.
Since my dataset could not easily facilitate this iteration, it was suggested at my first year assessment that I complete further data collection. However I questioned the ethical veracity of requesting the time of busy healthcare professionals or next-of-kin solely for this purpose (see for instance Bryman [259] comment on data redundancy in mixed-method research, p.111). Moreover, I did not feel that the absence of these interviews hindered my ability to develop theoretically derived conclusions. Interviewees had given rich accounts of admissions, and the sociological literature provided a solid foundation.

Furthermore, not concurrently interviewing and analysing afforded me an advantage. Gomm [253] has argued that “Delaying the making of analytic decisions until after interviews have been conducted may mean that different interviews take different paths, so that it may be impossible to find examples of variants on the same theme in all the interviews” (p.248). However, allowing participants to focus the interview on their own interpretation and causes of ‘inappropriate’ admissions, meant that in practice that I amassed a breadth of experiences that would have been difficult to achieve if I had focused on topics identified in early interviews. Whilst it meant I could not ‘test’ findings nor explore new areas not brought up by the data, I could be more confident that interviewee’s accounts reflected their own perspectives on admissions than if I had tailored the interview schedule.

2.4.2 The analytic process

I formally began analysing the ACE interviews in January 2015, but I had continued to engage with the participant accounts following the conclusion of the last interview. Sometimes this was through practical tasks such as anonymising the transcripts and preparing them for analysis. Other times I briefly returned to the transcripts for information in preparation for presentations. For most of the time though, the accounts tumbled unbidden throughout my thoughts as I engaged with the reading; examples sparking recognition between what I had been told and the experiences documented by others in both the sociological and end-of-life care literature.

The formal analysis was thematic in the broadest use of the term, and was later supplemented with purposeful reference to the literature discussed above so as to develop a theoretically informed view of hospital admissions that is situated in Meadowbridge but has relevance beyond it. I outline below the process I took.
2.5 Coding

Following anonymisation, I arranged each transcript to allow easy retrieval and facilitate coding, and checked the transcript with the audio recording for accuracy of the transcription and anonymisation [194]. On subsequent listens to the recordings I wrote spider diagrams with key points and pertinent quotes in order to regain familiarity with the interviews [194].

I then coded the transcripts, always first on paper and, after coding several transcripts, second using the analytic software NVivo. Coding twice gave me the opportunity to check that my coding was true to the dataset and did not represent what I wanted to find, a concern given that I had already formed general ideas about end-of-life admissions. I had planned to code entirely on paper but soon learnt that this would be cumbersome for thirty-three transcripts. NVivo allowed me to explore the data in the same way, but with greater flexibility and, once I had set up the codes, more efficiently.

The majority of the coding was ‘in vivo’, whereby sections of text were tagged or ‘coded’ using words and themes given by interview participants or descriptive phrases [260]. I trialled coding by more abstract themes derived either from participants or my reading (e.g. ‘professionalism’) but found it unsuccessful because the concepts I used were not sufficiently developed to be consistently applied across transcripts. I completed a sentence-by-sentence assessment of the interview, tagging each by the topic discussed. Each sentence, or series of sentences if the topic continued, could be tagged multiple times. The NVivo extract below (Figure 16) outlines this, with the vertical bars to the right of the text denoting coding, and the text on the top line referring to codes that had recently been used.
2.5.1 Subjectivity

Despite this sentence-by-sentence approach, my coding was an inherently subjective process and the way that I had coded the dataset was one of any number I could have done [253]. This became apparent when I asked Dr Walsh to code one of my transcripts to assess reliability, and the comparison of coding results showed a low inter-rater reliability. Whilst further coaching is likely to have improved this score - we often used the same codes for sections but varied in the quantity and scale of the codes - it demonstrates the fallibility of the coding process. To help address this I kept a record of codes and when they had been first used, initially on paper and later using NVivo in order to establish an audit trail [194], although day-to-day it was used as a memory-aid to prevent duplicate codes.

2.5.2 Speech

I also reflected on the macro aspects of the interview where relevant. It had been apparent during the interview process that there were variations in the way different healthcare staff spoke in interviews; particularly in terms of the vocabulary they used and the formality of their speech. This was most obvious between the two largest groups of staff I interviewed; the doctors and the ambulance staff. The ‘casual’ interview style of ambulance staff, whereby there was a greater use of acronyms and jargon, contrasted
with the ‘consultative’ style particularly used in senior doctor accounts, which often excluded, or translated without prompting, medical terminology [238]. These differences reflected in many ways Bernstein [190] elaborated and restricted codes and his work demonstrated the potential distinctions between the social context of healthcare staff. This was critical for highlighting variances in professional status, which I show in chapter 7 to be a significant factor in explaining the admission of case-patients by ambulance staff.

2.5.3 Mapping

After coding several cases of interviews, I mapped the codes I had developed, grouping similar items together. These sheets helped to gain an overview of the key topics of the first transcripts and, as I struggled to put codes into just one category, demonstrated how topics were related. I transferred this ordering of codes back into NVivo, creating a loose ‘coding framework’ with codes organised hierarchically. Thus for example, a code used in Figure 16 ‘hospital=acute place of care’ was within the ‘hospital’ group, which was a subsidiary of the group ‘place’. As I analysed more interviews I refined and adapted the coding framework; adding in new codes (which became less frequent with the later transcripts) and reclassifying code groups.

The mapping was at the general level; I chose not to distinguish between for example, case-patient characteristics such as disease or gender, or interviewee occupation, and instead viewed each interview as discrete data. Whilst some of these collectives did become an important way of understanding the admissions, this was not explicit until I completed the paper-clipping stage (see below). Viewing the interviews in this way was a further attempt to ensure that the analysis was guided by what interviewees had said and experienced rather than what I may have wished them to say. I may therefore have missed subtleties between groups. For example, the different diseases that the case-patients had did not feature as a finding. Realising this, I checked relevant coded content at the end of the process and found little evidence for the role of the diseases I had sampled for and the admission of the case-patient. I do not think this is a limitation of the analytic approach I took, but rather of the dataset itself, which was probably too small to highlight these differences, especially when case-patients had comorbidities.
2.7 Paper-clipping

Next I began to piece the dataset back together and frame it within the wider context of the reading I had completed. I recorded what I now knew about the admissions of the case-patients using spider diagrams. From here, I created an eight-box table (Table 6) outlining the topics covered in the interviews. To combine these topics with the reading I had completed, I undertook a process I termed ‘paper-clipping’. For each box I considered four resources; the theoretical literature I had read, general ideas I had recorded about end-of-life care, literature from end-of-life care and health services research, and the codes themselves. ‘Paper-clipping’ the various sources of information together in this way helped establish a theoretical justification to my arguments.

<table>
<thead>
<tr>
<th>Why admissions happen</th>
<th>How admissions happen</th>
<th>Hospital concerns</th>
<th>Time/Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>- not avoidable admission</td>
<td>- occur as soon as call made</td>
<td>- working out diagnosis</td>
<td>- how groups interact</td>
</tr>
<tr>
<td>- patient deteriorated</td>
<td>- ambulance struggle to stop them (professionalism)</td>
<td>- difficult to discharge ill patients</td>
<td>- poorly/’codes’</td>
</tr>
<tr>
<td>- insufficient nursing care</td>
<td>- hospital have to take patients in</td>
<td>- focus is on treatment</td>
<td>- preferences</td>
</tr>
<tr>
<td>- GPs need acute problem resolved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- patient not identified as end of life</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 6 Early findings

<table>
<thead>
<tr>
<th>What is understood by hospital/home as POD</th>
<th>How admissions can be prevented</th>
<th>Community concerns</th>
<th>Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>- hospital for patients with ‘survivable’ diagnosis</td>
<td>- earlier planning</td>
<td>- end-of-life care conversations hard</td>
<td>- sought from patients about treatment and preferred place of death</td>
</tr>
<tr>
<td>- hospital as place of safety</td>
<td>- more end-of-life care conversations</td>
<td>- insufficient community support</td>
<td>- Wishes for home are persuasive</td>
</tr>
<tr>
<td>- home is best</td>
<td>- greater community support</td>
<td>- only send in when have to</td>
<td></td>
</tr>
<tr>
<td>- home as risky for all HCP (GPS, hospital staff)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.8 Writing

The eight themes across the boxes in Table 6 eventually became three chapters which broadly consider the role of the hospital (chapter 5), the community (chapter 6) and the ambulance service (chapter 7). The content of these chapters was crystalised during the writing process as boxes expanded, contracted and merged together as similarities became apparent between them. This process started by reviewing paper-clipping of several boxes, and then drafting my findings. As I began writing, the analytic process evolved again, as I gained a deeper grasp of the data and recognised the intricacies and inconsistencies of interviewees’ accounts [261].
Sometimes I used the contents of the codes directly when completing boxes; reviewing the excerpts of transcripts and summarising the contents and illustrating them with quotations that best encapsulated the theme. At other times though, I realised that a discrete topic could not be answered by a single code or a summary of multiple codes and required an assessment of how they interrelated. I therefore looked again at the content within relevant substantive code groups (e.g. ‘community’), and re-coded it, this time by hand for convenience. I made paper copies of each code group, cut them into discrete excerpts and then sorted all these into piles, allowing excerpts to be in multiple piles where relevant, finally typing up the contents of each pile as a ‘new’ code to have a more permanent reference. Where relevant, I then completed a final analysis on codes to assess the rigour of a finding. For instance to assess the veracity of the statement ‘most staff thought home was an ideal place of death’ I interrogated the code ‘home is a good place to die’ by participant occupation and by case-patient diagnosis. From this re-coding I could then write a more comprehensive summary.

Writing facilitated synthesis by tying together themes which had seemed disparate. For instance, in chapter 5 I outline how hospital staff rarely saw the role of the hospital as either a place of safety or for acute care needs, but recognised both, although often struggled in their accounts to assimilate them. These tensions were difficult to distinguish in the analytic process where these roles were included as separate codes, but were drawn out in writing by comparing the codes together and being clear about what an interviewee had said about both. In this way, the process of moving from analysis to synthesis was not always of increasing abstraction as I had expected. During later stages of the writing process I returned to reviewing whole transcripts to assess the veracity of statements, particularly when I was describing group views. Perhaps as a consequence of the comprehensive coding I had done, there was a substantial number of codes that I did not synthethise into my writing because they proved to be only tangentially related to explaining admissions.

2.8.1 Quotations

When providing quotations in the following chapters I have sought to include sufficient text so that the context in which comments were said is clear to the reader. Quotations were chosen which best illustrate the point I wish to make, which inevitably means that some participant interviews are referenced more often than others, as is evident in Table 7 which outlines the proportion of quotations attributed to each participant. Those who eloquently explained an issue, or who discussed it in greater detail than others are
Chapter 4

overrepresented. In constructing this table I however reviewed transcripts of participants who were less often cited to ensure that their perspective was encompassed within the themes of the chapters, and where relevant amended the text and replaced or added in quotations. This process became an informal way of seeking ‘negative cases’ and lead to a more refined synthesis [262].

Some chapters necessarily draw more heavily from certain participant groups or from certain case-patients than others because their accounts were more relevant, such as chapter 7 which concentrates on the role of the ambulance service, and therefore focuses on the accounts of ambulance staff. Case-patients whose admission could be understood from a range of perspectives are drawn on more than those with only accounts from hospital staff.
I concluded my research by drawing out the persistent themes across and within the empirical chapters, exploring them sociologically in order to gain a greater understanding of hospital admissions. To do this I returned to the paper-clipping process and my reading notes, this time to establish the veracity of the synthesis. The product of this process is chapter 8. The aim of explicitly using theory was to help understand admissions not only within the context of ‘appropriate’ and ‘inappropriate’ but also as a
product of social interaction and restraint. By doing this I hope to have increased the transferability of my findings beyond the 9 case-patient admissions [194].

2.8.3 Summary

What is apparent from the above discussion is the tangled path that the analysis and synthesis process took, with much duplication and unused work. However, the process allowed me to identify and tease out the complexities in participants’ accounts and to become familiar with them. Whilst I sought for the analysis and synthesis processes to be steered by these accounts, they were not wholly dictated by it. Instead it was inevitably, and usefully, an amalgam of the coding framework I had constructed from the data and the knowledge derived from my interest in the end-of-life care and medical sociology fields in the preceding years.

3 Conclusion

The ACE Study dataset provided an opportunity to qualitatively explore hospital admissions; to understand how in practice admissions can occur, and to explore the roles of healthcare staff and families in making them happen. The use of a personally-collected ‘secondary’ dataset posed a challenge in terms of iteration, but was offset by the benefits of a rich dataset which gave me the opportunity to conduct an in-depth analysis and synthesis, which was also theoretically informed. By analysing data thematically, I could attend both to the stories of the case-patient admissions and to the experiences of the participants themselves as healthcare staff and next-of-kin. This cross-cutting analysis provides a nuanced view of end-of-life admissions, which helps to expand the scope of the understanding beyond the nine case-patients to other patients the healthcare staff had cared for, with relevance to end-of-life admissions more broadly.

With this foundation I can now explore the participant accounts. In the following three chapters I consider in turn the role of the hospital, the community and the ambulance service in the case-patients’ admissions.
Chapter five

“I can’t form a view from, in hindsight, as to whether he was so ill that he shouldn’t have come into hospital”

(21,3)
Chapter 5

Inappropriately admitted?
The role of the hospital

Hospital, it is broadly established in the policy literature, is neither a place where end-of-life patients should be cared for, or die. In the next three chapters, I explore the reasons why Mrs Brett, Hardwick, Tonelli, Williams, O'Sullivan, Thompson and Clarkson, along with Mr Saunders and French (collectively, the case-patients) were admitted shortly before their deaths to Meadowbridge.

In this chapter I explore the role of the hospital in their care, assessing the way staff from a range of occupational roles described the hospital. I begin by considering the role of the hospital in accepting the case-patients. Next I establish whether hospital was conceived by staff to be primarily for acute care provision, and in this context, how their deaths in hospital were considered. It was apparent from interviewee accounts that hospital for the case-patients was not wholly about clinical care, so I also consider the role of hospital as a place of safety. I then evaluate the potential benefits staff thought hospital offered the case-patients compared to the opinion of next-of-kin.

I conclude by considering the appropriateness of the case-patients’ admissions, and find responses reflected the emphasis staff placed on the role the hospital was thought to have performed for the case-patients. In practice, the terms ‘appropriate’ and ‘inappropriate’ fitted poorly with the factors involved in their admissions, and masked the varied ways in which the hospital fulfilled the patients’ care needs.

Accepting patients

The problematic proportion of end-of-life patients in hospital is framed in policy in terms of admissions. ‘Admission’ implies that patients’ entry to hospital is as a direct result of a decision in the admitting department, and in the context of pejorative end-of-life admissions, where this permission was incorrectly given or made. In practice however, hospital interviewees in the study described admission of the case-patients as inevitable and unavoidable; a non-decision. Staff described patients as too sick to not be allowed
entry or inappropriate to then return home (and often both). In the following section, I outline how and why this was so, and consider the uneasy feeling interviewees described in admitting these patients.

1.1 Discharge not admission

The case-patients admissions all occurred in A&E, a pattern reflecting national trends. When I asked interviewees about the case-patient admissions, their answers were often paradoxically framed around discharge. For example, not admitting Mrs Brett to her speciality was not an option for ward doctor Dr Patel:

“SH: What kind of factors influence that decision [to admit her]? Was it purely clinical do you think or...

AP: Well she, you couldn’t have sent her home, there was no facilities to send her home, she needed symptom control, she needed rehydration and she had a life threatening condition in terms of her blood results needed sort of management, you, she was in no state to go, she wouldn’t have been able to walk out, you know, yeah.” (2,5)

For Dr Patel, not admitting Mrs Brett to hospital would have meant that she would not have received the care she needed. Admitting Mrs Brett was not a positive choice, because “you couldn’t have sent her home,”(2,5) but rather a necessity to ensure her care, a sentiment prevalent across all of the interviewee accounts.

Dr Patel justified Mrs Sullivan’s admission to hospital by emphasising her clinical duty. She constructed Mrs Brett’s admission as a life-and-death decision by framing it around insufficient community provision. Either Mrs Brett would have her “life-threatening condition”(2,5) treated in hospital, or she would die. That Mrs Brett was terminally-ill (as recognised by her GP) was outweighed by her immediate needs, which could only be addressed in hospital. Dr Patel also emphasises an obligation to care for Mrs O'Sullivan; she “was in no state to go [home]”(2,5). These dual emphases, of clinical necessity and moral obligation, were present in varying proportions in all of the accounts. These are illustrated in the various reasons hospital staff gave for not sending a patient home, as many, like Dr Patel, responded to questions of admissions with replies about why discharge was not appropriate.

Some patients could not be discharged as a consequence of receiving treatment in A&E. To transport Mr French home for example, would have meant stopping his treatment, probably resulting in his imminent death. For other patients like Mrs Tonelli, there was a concern that they would die on the way home because they were so close to death when
Chapter 5

they arrived in hospital. Interviewees were also concerned about the availability of care at home, which was presumed to be inadequate because the patient had been brought to secondary care. The A&E doctor caring for Mr French, Dr Cartier, said for instance that “It's very difficult to send them home from A&E unless they've got a really, really good set-up at home, in which case why are they even coming to hospital?”(20,7). As Dr Cartier went on to explain, the ‘setting up’ of community care from the hospital would have taken more time than the four-hour window available to meet government targets to decide whether to admit Mr French, and longer than he thought Mr French would be alive for (see chapter 6, section 3.3 for further discussion on the problem of setting-up services). In practice, these reasons meant that patients were admitted “too late”(20,9) to be returned home and as a consequence, they had to be admitted.

The moral justification to admit case-patients suggested by Dr Patel was present in other cases. For instance, when discussing the idea of patients dying at home and being cared for by their family, the ward doctor caring for Mrs O’Sullivan, Dr Parr said:

“SP: So whether the aim would be to try and improve the services so that people can manage [to care for a relative at home], or, you know, then that's something to look at, but I don't think that we should have a policy of turning people away at the door if they've got these things in place because someone has phoned 999 for a reason, and if they feel they can't manage that situation that's not an appropriate situation for someone to die, doesn't know what to do, can't manage, can't cope, it's just totally unnerving for the patient who's dying and I don't think, I don't think that's…”(32,7)

Dr Parr framed not admitting an end-of-life patient as a refusal of help, of “turning people away at the door”(32,7). If patients were in need, Dr Parr’s comment implied, there was a responsibility as a hospital clinician to care for them. Refusing admission would have been to deny that responsibility. Even strong advocates for case-patients not coming to hospital, such as Nurse Jones, a specialist nurse for Mrs Thompson who wanted her to stay at home, felt that it would be “inappropriate”(11,8) for patients to be sent back to the community rather than be admitted once they had arrived at hospital. Arranging alternative community care was therefore necessary if patients were not admitted, in order to meet this clinical duty.

1.2 Hospital responsibility

This obligation of care was far-reaching, as explained by the ward doctor caring for Mrs Thompson, Dr Khan:
“SH: And the decision to admit her in ED are you...?

MK: I think it’s difficult, you can’t turnaround someone who’s gasping, you can’t just turnaround these people and send them back home unless, and this is where it becomes sometimes easier, and again it’s an anonymous scenario. I have had patients who came in who weren’t doing well, knew they were going to die and I have managed them, managed to get them fast tracked home so that they could die in their new brand new conservatory looking out across their garden that they’d just be doing, to die in a way that they wanted to die. And the family moved, you know, as much as they could to do that and to get them home and I was worried that the patient might die on transit back home but got to go home, died in their brand new conservatory, looking across their garden and the family were so happy, the patient was so happy. But these discharges in extremis carry significant risk, there’s a risk of the patient not actually living to a point that they can be leaving hospital, dying en-route and when they arrive having an unpleasant death that distresses the family as well as the patient. So often we feel not in control in that circumstances and sometimes you take a risk because that’s what the patient wants and the family wants but taking that risk is sometimes very difficult for consultants. It’s definitely difficult for registrars and impossible for senior trainees. So I think were this lady to have gone home, the answer is no unless the family were accepting that she was going to die, they wanted her home to die and we could guarantee that she wouldn’t die on route back home. And I don’t think any of those were clearly evident reading the discharge letter.”

In the next chapter I explore the reality of home as a site of death, but here it is relevant to explore Dr Khan’s construction of “risk” at home. Home is a problem because hospital staff “often [...] feel not in control in that circumstances, and therefore cannot ensure that a patient will not have an unpleasant death.” His concern for the anonymous patient he describes, and the efforts he went to ensure her care, demonstrate the reach of hospital responsibility far beyond the physical site of the hospital to, in this instance, a “guarantee[d]” death at home.

This extended responsibility has been identified elsewhere. The recent Parliamentary and Health Service Ombudsman report [264] on ‘unsafe discharges’ from hospital for instance illustrated the problems when this onward care was not appropriately organised. The implicit expectation is that patients should not be discharged from hospital unless their clinical condition is stable and, where relevant, suitable onward care is in place. The report confirms the significant reach of the hospital responsibility. The start of this responsibility, Dr Khan’s account illustrates, is as soon as a patient arrives in hospital. Patients who are close to dying, “who are gasping” cannot be ‘turned around’ and sent back home, unless their safety can be assured.

In this context of duty it is unsurprising that patients close to the end of life were admitted. Admission seemed to be “less risky”, in Dr Khan’s terminology, than sending a
patient back home. In addition, it was simpler administratively. As earlier established, arranging alternative community provision from A&E was near impossible within the short timeframe available and was a task that was clearly an exception to normal duties and rarely performed. This matches a conclusion of a national study of six hospital sites which found that “it was quicker and easier to admit to a hospital bed, and this often inspired more confidence in A&E staff worried about whether community services would be available if they sent a patient home”([265]p.48). It may be therefore that rather than an admission decision not being made, the decision to admit seriously ill patients was so routine that it was presented as being a non-choice. Regardless of how this decision is framed, the consequences to the case-patients were the same; admission was inevitable.

This inevitability about these admissions did not, however, necessarily legitimise the patient’s entry to hospital. Mrs Williams’ admission explains this further, as A&E doctor Dr Singh, explained:

“SH: And do you think the admission was in any way avoidable?

AS: If the prior... as I said, if the prior decision in the community had been made and if there are enough resources in the community, a patient would not be needing to come to the hospital at all.

SH: But in the circumstances?

AS: In the circumstances, no. I think once a patient has come into the A&E, I think there’s no other... We could not send the patient back to the home in that situation. I think... you know, transferring or being on the transport for a patient in that scenario is not good. So I would keep her wherever the patient comfort is.”(26, 4)

Dr Singh did not think Mrs Williams should have been in the hospital. He felt that if appropriate care in the community had been arranged, she “would not be needing to come to the hospital at all”(26,4). However since Mrs Williams was ill and could not be sent home (thus fulfilling the hospital responsibility terms identified above of clinical need and available care), he felt she had to be admitted. In the next section, I explore the reasons why staff thought end-of-life patients should not be cared for in the hospital.

2 The undesirability of dying in hospital

Despite the admission of the case-patients, interviewees often expressed discomfort about their presence within the hospital setting. Whilst it was recognised that patients were in need of care, there was a general consensus that hospital was not where they should be receiving it, nor what the hospital model provided well for, reflecting policy
rhetoric (chapter 3). I explore next the ways that hospital was considered a poor place for end-of-life patients to be cared for, related to the purpose of the hospital, the quality of the patient’s death, and the cost to the service.

2.1 End-of life care patients should not be in hospital

Mrs Tonelli had dementia and was admitted to the hospital from a care home. When she was received from A&E, her ward doctor Dr Graves, stated; “it was clear from clapping eyes on her, just from the end of the bed that this lady was dying”(24,2). Patients like Mrs Tonelli probably should not be in hospital Dr Graves explained later in the interview:

“SH: And stepping away from this lady’s case and more broadly thinking about quality and the idea that we seem to have that admissions where people die within three days are undesirable, what do you think about that?

SG: I think they fall into two main categories, so you’ve got the category of people who come into hospital and die within three days but actually they were on full active treatment so you were doing something about it and you really wanted to get them better but unfortunately they were so sick you couldn’t, and I think is completely appropriate, they should definitely be coming to hospital and we should definitely be trying to save their life. I think it’s very demoralising when you’re in the emergency department and particularly for me as a geriatrician, but I think for others as well, when you see someone who you’re clearly, even from the outset know that you can’t save this person’s life and that actually it is not in their best interests. It’s sometimes difficult when you have family attached to that person and they’re not in the same place, they’re not ready for this person to die and they don’t understand how severely ill they are. In that instance you’re not just treating the patient, you’re also treating the family and in some respects if it gives them a better death and the patient is not suffering then it might be appropriate for them to come to hospital. But if the family don’t have strong views or big expectations and it’s the patient’s wish, or the patient is not able to tell you or it’s clear, then actually those ones it’s just wrong, and they could be much better managed and more appropriately in the community. But I think there has to be the support there and there has to be the understanding in the nursing homes that people do die there as well.”(24,5)

Inherent in Dr Graves’ account are the tensions of the reality of caring for end-of-life patients, which I return to later in this chapter. First I consider the significance for the role of the hospital of end-of-life patients being in hospital. Dr Graves’ comment presumes that is there is more appropriate care elsewhere for patients like Mrs Tonelli, a point I explore below. From this standpoint, hospital is an inappropriate site of care. Dr Graves’ comparison of patients “on full active treatment”(24,5) is that those who cannot be cured should not be in hospital. This distinction makes acute care provision a primary role of the hospital, and means that patients like Mrs Tonelli being cared for in hospital is “just wrong”(24,5).
Chapter 5

This challenging contention does not mean that those in hospital at the end of their life were not considered patients by interviewees, nor that they were not offered care, but rather that this provision was not considered to be appropriate business of the hospital. Mrs O’Sullivan, for example, like Mrs Tonelli had dementia and had arrived in hospital from a care home. Whilst she was treated in hospital with intravenous antibiotics for a chest infection, Dr Choudhry, her ward doctor, later said that really “She should have been managed as a palliative patient in the home”(30,3). Whilst Mrs O’Sullivan was “a common elderly lady that comes onto the ward”(30,1), palliative care was not the main aim of the ward according to Dr Choudhry:

“SH: There is an assumption, that hospital deaths are... where it could have been... where it’s an end-of-life patient, which to some extent it could have been predicted, are inappropriate, and I’m just trying to understand the many different ways why that is so in comparison to the home.

PC: Why it’s inappropriate? Yeah, I think it’s the staffing, so they’re just... they’re not... Say if you go to a hospice, the nurses there and all the staff there are all geared around that end-of-life care, whereas here... it’s different if you go to a different ward, I suppose, but yeah, they can give end–of–life care, but they’re more geared up to giving other care. So I suspect the end is different. That’s the thing that’s the difference. And the doctors that look after the patients on the generic wards are not necessarily... so they’re not palliative care doctors, they don’t know these patients very well on an acute medical ward, so... where the turnover’s very high and, you know, you’re not gonna begin to be able to know them as well, you know, their family, and get that rapport that you would, the GPs would have, or I don’t know, other community doctors at home.”(30,5-6)

An end-of-life care patient like Mrs O’Sullivan, for whom there was little chance of getting better, was therefore construed as an interloper, even if her case was not unusual in terms of typical ward patients. For Dr Choudhry, the speciality ward she was on was “more geared up to giving other care”(30,5-6), rather than palliative care, and when it did provide it, it was less good than palliative care provided in hospice or the community.

It was in this context of supposed poor end-of-life provision, and the lack of fit with the main acute aim of the hospital that Dr Hennessy said that patients for whom it was decided that “whatever we do [in the hospital] is not gonna help and they, did they really need to come in in that case when all we’re doing is, all we’re doing is palliation”(21,9). Dr Hennessy makes explicit what is implied in Dr Choudhry’s and Dr Graves’ accounts: dying patients were undesirable in the hospital because they only required palliative care and did not need acute care. This distancing of end-of-life patients and hospital provision was justified in their accounts because it was presumed that better care could be provided for them elsewhere (see also chapter 6). Next though I explore the view that
end-of-life patients may not be beneficial for the hospital, and afterwards, that hospital may not be good for end-of-life patients.

2.2 Hospital costs

The accounts of Dr Graves, Choudhry and Hennessy echo those of other interviewees in stating that hospital was not the most appropriate place for the case-patients to be receiving care or dying. Whilst they and other interviewees did not advocate for the exclusion of the case-patients from hospital on the grounds of financial or capacity costs, it was also apparent that their exclusion was not wholly to do with concern for the patients’ wellbeing. The cost instead was to staff; as Dr Choudhry noted above, end-of-life patients were recognised to be difficult to care for, and it was not care all staff felt able to deliver satisfactorily.

Arguments about financial cost and hospital resources were raised rarely about the presence of case-patients in hospital and then primarily only as a corollary of the contention that as end-of-life patients who did not need acute care they could be better cared for elsewhere. For example, ambulance staff (AS) Lunn stated:

“SH: There’s a push to have fewer people dying in hospital and more at home and do you have an opinion on that?

NL: Yeah, I’d like to I suppose understand the rationale more about it, the rationale’s because that’s where people would like to die and that should, you know, it should be respected and that’s either a hospice or in their own home and where possible that should be supported. But I would hate to think as a service provider it was being made along the grounds of this is an undesirable admission on a basis of we’re not ever going to really be able to do anything for this patient and therefore it’s a costly kind of intensive financial kind of driven decision that goes along it, with it, which at the same time on the flipside of that I can see why effectively that could be for people running a service at a strategic level, if that’s a consideration for them as well in terms of, you know, the resources they’ve got about making sure that the spread of those resources is appropriately allocated as possible, does as much good I suppose.”(19,10)

AS Lunn’s acknowledgement of the financial incentive for not caring for end-of-life patients in hospital was not proposed by him as an argument that would change his practice about these patients in order save the service money; in fact, he “would hate to think”(19,10) that decisions were made under this justification. Instead his account demonstrates further the argument that being in hospital offered little to the patient because “we’re not ever going to really be able to do anything for this patient”(19,10).
Chapter 5
In general the unfavourable presence of end-of-life patients in hospital was instead typically discussed in terms of the difficulty of providing appropriate support. Thus an A&E doctor caring for Mrs Williams, Dr Kennedy discussed:

“SH: Stepping back, then, and thinking about policy more broadly and the idea that admissions where people die within three days are deemed kind of undesirable, what do you think about that?

AK: Yeah, I mean, I’ve seen... The reason I’m finding it difficult to remember this one is because I’ve seen one that was very similar that when they came in I just thought, “You’re dying. I could give you antibiotics but it won’t make a blind bit of difference.” Yes, and so they’re very unsatisfactory to care for, because you know the patient’s endured an ambulance journey which is uncomfortable, the family have all been called in a hurry to the hospital, we can deal with them, we do a reasonable job, but I suspect for them it would be nicer to be in a home where they know the staff anyway with a bit of extra nursing support. It creates a certain amount of work for us that’s not... It’s what we’re there to do, but it does create a certain amount of work. It’s one-to-one nursing for this patient. And they’re in an unfamiliar environment, so if they do come round I suspect they’re not... we’ve contributed a bit to their distress. Hopefully they’ll have family there by that stage, but they’re in an unfamiliar place so... It’s very unpleasant dealing with people, particularly when as a senior I usually arrive, come to the end of the bed and go, “You’re dying,” and it’s all too late.”(25,4)

Dr Kennedy rehearses problems outlined about why hospital is a problem for dying patients which are discussed in greater depth later. Of relevance here is the problems she identifies for staff. End-of-life care patients are “very unsatisfactory to care for, they create a certain amount of work”(25,4) and use up nursing resources with one-to-one care. In part, Dr Kennedy’s comments parallel well-rehearsed arguments that if end-of-life patients cannot be ‘saved’ they fit poorly into the premise of the acute setting of the hospital and in particular the A&E department (e.g. [266-268]). As a consequence these accounts suggest, such patients are considered a burden, taking up staff attention from those who can be ‘rescued’. But Dr Kennedy’s comments are not primarily a narrative of ‘saving lives’ but of frustration and disappointment that since the care provided in hospital “won’t make a blind bit of difference”(25,4) it would be “nicer” for the patient to be cared for in the community. In turn, the “unpleasant[ness]”(25,4) for Dr Kennedy of dealing with patients like Mrs Williams suggest a conflation between the patient themselves and the negative labelling attributed to them as someone dying in hospital who cannot be ‘saved’ and the difficult situation this puts staff in, particularly when this is tangled with beliefs about professional neutrality. I pick this latter point up in chapter 8 since it is helpful for gaining a greater understanding of why the case-patients were considered in some way ‘unwelcome’ at Meadowbridge.
My contention that hospital is generally not ‘right’ for end-of-life patients excludes a number of tensions inherent within the above accounts that I will return to later in this chapter: that there may be some circumstances where end-of-life patients are welcomed in the hospital and their admission beneficial to them; that ‘save-ability’ is an important aspect to justifying admissions and the presumption that admissions were the consequence of inappropriate community provision. Next though I explore why hospital was not thought to be desirable as a place of death.

2.3 Hospital: A miserably lonely place to die

The concept that hospital is a poor site of death is inherent within the idea that end-of-life patients should not be in hospital (chapter 3, section 2.2.1). Interviewees, especially community staff, often gave emotive responses about dying in hospitals. For GPs, deaths in hospital could be “miserably lonely”(28,8), “pretty horrible”(15,7) and for Dr Chapman caring for Mr Saunders, the idea of it “filled [ed] [him] with horror”(10,4). Often these comments stood alone, but where staff gave tangible reasons for these responses they related to the hospital environment and unfavourable comparisons to home.

The case-patients dying in hospital necessitated not dying in their own bed (and worse, in an acute bed) and being less comfortable than home. It meant it was harder for their family[49] to visit or to be present at the death and was considered by AS Watts, to simply be “not dignified”(12,6). As well as accentuating to patients that they were not home, hospital was also thought to be a problem because of the very ‘hospital-ness’ of the hospital. The environment was timetabled, anonymous, “alien”(23,6) and noisy and filled with “hustle and bustle”(12,3).

Hospital also meant clinical care, which was not always welcomed. Being in hospital, for example for Nurse Jones, meant that Mrs Thompson had had to endure “having needles stuck in her, doing blood gasses and whatever else they were doing”(11,5), whilst the focus on curative care more generally was recognised to lead to contradictions of care priorities by the pastoral worker Mr Allen. For others, the concern was insufficient hospital provision: Dr Chapman’s horror of hospital was attributed to his concern about insufficient nursing and lack of effective communication between staff. The hospital itself was not a unified concept and some areas were thought to be worse places for the case-patients to die than others (A&E was particularly singled out as embodying the problems of hospital). The reach of the hospital, as with its responsibility, extended beyond the physical site. The problem of the hospital death encompassed uncomfortable
ambulance journeys (Mr Saunders was “bumped down the road”(5,4) from his home to the hospital according to Dr Chapman) and multiple transfers before a patient reached the ward. For Mrs Thompson’s GP, Dr Fraser her hospital visit “involve[d] ambulances, an admission to A&E, an admission up to the ward”(10,5), all of which were deemed to be undesirable for the patient.

These concerns match arguments made earlier about the undesirability of hospital as a site of a not ‘good death’ according to government rhetoric and prevalent within the academic literature (e.g. [269]; chapter 3, 2.2.1). What is pertinent about the interviewees’ comments is that they were made in the context of end-of-life hospital admissions. Their comments establish that the admission of the case-patients were not in order to achieve an idealised notion of a good death in hospital. If, as AS Simons contended, “hospital isn’t the right place to be dying”(23,10), then hospital must have been used despite these problems, a point I explore further in chapter 6.

2.4 Conclusion: Inevitable admissions, treatment and a poor site of death

The admission of case-patients was often not recognised as a choice. These admissions occurred because either patients were recognised to have a clinical need for hospital care or because it was considered inappropriate to send them back home; or a combination of both. Whilst the case-patients were sometimes recognised to be a cost to the hospital, staff were more concerned that patients could be better cared for in the community since treatment was futile and hospital was perceived to be a poor site of death. However, not all of the case-patients were considered to be in the ‘wrong’ place, and I explore why next.

3 Welcome patients

3.1 Acute needs

Some case-patients were thought to be wholly appropriate for hospital care. Mrs Brett for instance had recently received a cancer diagnosis and she was admitted to hospital shortly after this, following a home visit from her GP. Mrs Brett needed to be in hospital according to her ward doctor, Dr Patel:

“SH: OK. Clinically, did [Mrs Brett] need to be in hospital?

AP: Based on her results, yes, she had, she was also quite symptomatic, even from the cancer point of view, and that would have needed inpatient treatment because
I don’t believe there was anything set up in the community ‘cos she was only really diagnosed a couple of hours ago in the meeting, so there wouldn’t be anything in place to manage her, and to be honest, she was probably too sick and too acutely sick to be managed in the community, so that to make sure that she was going to be kept comfortable it would have required a hospital admission.”(2,2)

Dr Patel justified Mrs Brett’s admission to hospital primarily in terms of clinical need: she was “too acutely sick”(2,2) to be cared for at home, so unwell that being at home would have meant that she would not have been “kept comfortable”(2,2). (This also relates to a concern about community provision, which is explored in chapter 6). As established earlier, Mrs Brett’s terminal status was considered separately to her “life-threatening”(2,5) problems which needed to be resolved in order for her to be “comfortable”(2,2) and for Dr Patel, the best place for this to happen was in hospital.

The need for some patients to be in hospital was so evident to some staff that it could lead to awkward exchanges like this, with Mrs Hardwick’s A&E doctor, Dr Young:

“SH: And the implications for that?  
SY: So it’s, it was very serious and unlikely to survive without major cardiothoracic surgery.  
SH: Okay. So she’s in a very serious condition.  
SY: Yeah.  
SH: So this is perhaps very obvious, did you want [Mrs Hardwick] to be admitted? Because that’s part of your role isn’t it...  
SY: Yeah, yeah absolutely.  
SH: To make that decision? And I’m going to ask you an even more silly question of why?  
SY: She’d unexpectedly become seriously unwell.  
SH: Did you expect her to leave hospital? Did you expect her to be sent home eventually or?  
SY: No. To be honest once we’d... so initially when we didn’t have a diagnosis we weren’t sure but once we’d made this diagnosis, it would be a case of either her having surgery that she’d be unlikely to survive or not having surgery and being certain not to survive so the options were pretty bleak at that stage.  
SH: And what is the kind of timescale once you’d diagnosed this problem. I mean are we talking weeks or is it days if she doesn’t have surgery?”(16,3)

Dr Young was definite that Mrs Hardwick should be admitted, and as a consequence my questions about why she should have been admitted came across as illogical; since Mrs Hardwick had “unexpectedly become seriously unwell”(16,3) her symptoms needed to be diagnosed, and the best place for this to occur was the hospital. As with Mrs Brett, Mrs Hardwick’s clinical need justified her admission, and her limited prognosis was not considered significant to the decision. Both patients demonstrate how the desire to not have end-of-life patients in hospital could be overruled by an opposing need to establish the diagnosis or address the symptoms of the case-patients.
Chapter 5

The accounts of Dr Young and Dr Patel also provide useful nuances to the idea that hospital was undesirable at the end-of-life. Whilst it was recognised that both Mrs Brett and Mrs Hardwick were likely to die in hospital, their acute condition meant that hospital was framed as a necessary place of care. This point is often missing in arguments about the ‘out-of-place’ status of older patients in hospital, where it is assumed that ‘somewhere else’ would be better for them than being cared for in hospital (e.g.[270]) by showing that these admission are not wholly orientated around ideas that patients were reluctantly admitted. Moreover, their care suggests criteria for ‘appropriate’ admissions of the case-patients. Building on earlier conclusions, whilst hospital was broadly recognised to be not an ideal place for end-of-life care patients, severe medical symptoms, often combined with a need for clinical investigation were an important qualifier. In these situations, case-patients were not only admitted, but were accepted with a moral need to be in hospital.

3.2 ‘Survivable’

Mrs Brett and Mrs Hardwick were both admitted to hospital because of a perceived immediate medical need for them to be there; conditions that were respectively considered “life-threatening”(2,5) or that required urgent surgical intervention. However, it was not only urgent symptoms that were recognised as necessary for hospital treatment, the likelihood of a patient surviving their hospital admission was also a consideration for staff. This justification was used by ambulance staff to warrant bringing a patient to hospital, and by ward doctors in particular to explain why an admission was permissible, if not appropriate. It was a reason that was particularly demonstrated by one of the ambulance staff involved in Mr French’s admission, AS Darby:

"SH: If you hadn’t have taken him in, do you think he would have died fairly, how long do you think he would have lived for?

KD: [comments on consequences of particular illness] it would have probably have been that day or at the latest probably the next day anyway. I imagine probably later on that day without treatment. But because it was something that can be treated and it, although it was loosely connected with the COPD it was sort of separate, if that makes sense? So he wasn’t going there [hospital] because he had an exacerbation of his COPD but he was going there with something that was loosely connected to, you can get it because of, but it was treatable. So obviously you can offer appropriate treatment there. If we’d have gone to somebody that perhaps didn’t have, you know, had exacerbation of COPD and we tried everything and he was terminal and then maybe we would have perhaps got admission avoidance or someone in, you know, you can get the matrons, community matrons come out?"
SH: Oh okay.

KD: But the fact that he had a treatable condition meant that we would treat it. And at that stage although he had chronic condition he wasn’t necessarily at end of life.”(18,2)

Whilst AS Darby recognised Mr French was dying, his symptoms meant she did not think it appropriate to treat him as an ‘end-of-life’ patient. As such, hospital was necessary, and would be morally reprehensible if denied. This view was shared, if less emotively, by other ambulance staff. AS Watts, when discussing that he was would go against the dominant view and keep patients at home50, stated he would only do so if the patient did not have a reversible symptom that could be resolved by hospital care.

Similarly, for hospital staff, the ‘reversibility’ or ‘treatable’ nature of a condition or symptom meant that it was acceptable for the patient to be in hospital. Thus Dr Young concluded that whilst Mrs Hardwick’s heart condition happened to be “un-survivable for her”(16,8) for others it could have been treated, whilst Dr Price, A&E doctor, established Mrs Thompson had a “reversible”(13,5-6) condition meaning that hospital was an acceptable place for their care. Similarly, Mrs Clarkson had a condition which could have been treated according to the ward doctor Dr Browning. Hospital was therefore a welcome place for case-patients who could be classified as having a curable condition, whatever the odds of survival. But care was still tempered according to need. Mrs Clarkson for example was considered by Dr Cook, ward doctor to not be “an ICU candidate”(7,3) whilst recognising that this would be where there was the greatest chance of survival.

The emphasis on the dual aspects of time and reversibility could subordinate a case-patient’s end-of-life status in the same way as a life-threatening condition. As a consequence, hospital became a more acceptable place of care, with concerns about its undesirability as a place of death diminished. This was in part because their care needs were considered legitimised for hospital care. A case-patient being urgently ill, or with a condition that was thought treatable meant something could be ‘done’ for them, in contrast to the frustration of caring for dying patients for whom hospital care was thought to be ineffective.

This distinction about the provision of care did not mean however that staff wanted to provide medical treatment to patients at all costs, as Chapple [266] argues occurs in United States hospital care with the dominance of a ‘rescue’ culture. In contrast, hospital interviewees were keen to emphasise the treatment limits for case-patients. Even when
patients were on active treatments (typically antibiotics) there were clear limits expressed (often referred to as a ‘ceiling of care’). As well as physiological markers, patients’ discomfort and distress (as defined by the interviewee) were identified as indicators to change from active to palliative treatment. There was also frequent discussion of Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) orders being written for patients. All of these factors imply that ‘saving’ palliative patients was not an interest for hospital interviewees. Instead, their concern was in facilitating an ‘appropriate’ death, whereby invasive treatment is minimised, and ‘unnecessary’ treatment halted [1].

Ultimately, case-patients were accepted as appropriate hospital patients where clinical need could be demonstrated, either through the need for urgent care or investigation, or where patients had symptoms that could be improved using hospital resources. I explore next how hospital could be recognised by staff as an acceptable place for case-patients even where no clinical need could be demonstrated.

4 Hospital as a place of safety

Hospital could be a haven for case-patients whose needs were not thought to be appropriately met in the community. This conception stood in apparent contradiction to the construction of hospital as primarily about meeting case-patients acute needs, but in practice staff often drew on both interpretations to explain the admission of the case-patients to hospital. In the following section I explore how hospital staff felt an obligation to provide care to case-patients thought to be in need, and how community staff drew on these resources by referencing the hospital as an emergency reserve.

4.1 An obligation to provide care

Hospital interviewees established that regardless of acute need, the hospital had a moral obligation to care for end-of-life patients if they were in need. Provided healthcare staff facilitating the admission could demonstrate that the case-patient needed to be in hospital, and where the need was loosely clinically orientated, then the role of the hospital was to accept these patients. Thus hospital becomes a provider of emergency nursing care, of an available bed for patients and of reassurance and relief to families, as a ward doctor for Mrs O’Sullivan, Dr Moss explained:

“SH: Even if those reasons are not medical, perhaps social or you know or family not being able to cope?
JM: Yeah, we admit patients for far, far, you know, not, not in an end-of-life care situation, but we admit patients all the time for social reasons and hospitals are places of safety and that should be every bit as true in the final, if not more true in the final hours of someone’s life as it is when they’re, you know, 75 years old and getting a bit infirm and the daughter is away on holiday and you know, the medications have run out and, and, the patient can’t get down to the pharmacy, we do that all the time and I think it’s really important that we continue to provide that, that, you know, ultimate point of safety and I think it’s almost a point of pride that we can, you know, when everything else fails, we are there and we should be providing good quality care for these people.”(31,4)

These two conceptions of the hospital – as a place for acute care and a place of safety - were not necessarily contradictory for staff and could be operationalised together by emphasising that the community could not fulfil all of a case-patient’s needs. Thus Dr Moss could argue earlier in the interview that end-of-life care patients should not be cared for in hospital, but at the same time state that it was “a point of pride”(31,4) that hospital should be available to these patients if “everything else fails”(31,4). The way in which care could ‘fail’ is considered in detail in the next chapter.

4.2 An emergency resource

The caveat of community failure outlined by Dr Moss was recognised by other interviewees to explain either why case-patients were cared for in hospital (primarily hospital interviewees) or why they had been sent there (community interviewees). This justification of these admissions as exceptions maintained the primary status of the hospital as an acute care provider. For example, in the case of Mrs O’Sullivan, all of the alternative places she could have been cared for were listed prior to an explanation of why she was sent in to hospital by her GP, Dr Abramson:

“SH: Do you feel the admission was appropriate?

CA: Well, it is in the sense I’ve got no alternatives. You know, the alternative is for her to die without nursing, without anything. So I can’t leave someone that sick to die unattended in their bed, so from that point, yes, although unfortunate. It would be better if [Hospice] had a bed or if the [Care Team]... Or [Hospice] can be a bit funny, though. [...] I mean, [Hospice] quite likely would just say, “No, we’re not going to be involved in that.” So... I mean, [Hospice] has to defend... you know, they do quite aggressively defend their beds, and quite rightly so. There’s very limited provision. [...] It was a... it was a bit academic, because they didn’t have a bed anyway.”(28,4)

It is important that Dr Abramson demonstrated the alternative places of care she considered for Mrs O’Sullivan before she sought hospital care. The use of the hospital only as a last resort is fundamental for the conception of hospital as a place of safety as well as maintaining the acute role. Its availability as an emergency provision relies on
the idea that it is not routinely used for non-acute needs. In this way the two roles may be mutually associated. Defining the hospital as primarily a place for acute care helps to discourage admission for non-acute need and to manage capacity. Importantly, ‘emergency’ admissions could be for patients with acute needs, or those where community staff had “no alternative”(28,4). Evidence for this can be seen in the distinction given about where symptom care should occur for patients like Mr Saunders by his ward doctor, Dr George:

“SH: No, I know. It doesn’t, to some extent it perhaps doesn’t matter how neatly guided that process is, if something happens or a patient feels uncomfortable then hospital has always got to be an option?

RG: I wouldn’t say hospital always has to be an option because there might be other ways of actively supplying support, so I might put it differently and say if someone is dying it must always be an option that their symptoms can be relieved through expertise to do that. And it happened to be that hospital provided that with this caveat that his initial treatment was active treatment rather than palliative.”(5,6)

For Dr George, hospital was a resource that offered symptom control, but should not be considered the only option where patients’ needs could not be met. Dr Abramson’s extended justification for why she had sent Mrs O’Sullivan to hospital indicates that she may have felt the admission challenged norms of the hospital that were only partly absolved by her claims for Mrs O’Sullivan’s emergency status. As shown previously, this concern was valid, as hospital interviewees were disapproving of case-patient admissions from the community that they felt were not appropriately medically justified.

5 The benefit of dying in hospital

There was, though, an acknowledgement by interviewees from all settings that hospital could provide an acceptable death and a recognition that there may be some benefits to dying in hospital for both families and patients.

5.1 For the patient

Healthcare staff acknowledged that a death in hospital may have offered some benefits to the patient. These were primarily construed from the premise that care at home would not have met patient needs, and therefore the clinical provision of the hospital was emphasised. Hospital offered pain management, the provision to quickly control symptoms, and palliative care resource. Hospital was also thought to offer reasonable comfort, and for regular hospital visitors, familiarity, and for those case-patients thought to be living alone, to offer limited companionship. As a consequence of these factors,
dying in hospital was considered by some interviewees to offer case-patients dignity in
death.

For most hospital staff, the deaths of the case-patients in hospital were simply
satisfactory. Mrs O’Sullivan’s death for example, was “managed fairly well in the
circumstances”(30,7) according to Dr Choudhry, Mr French’s was “as good as we can
offer”(21,4) according to Dr Hennessy, Mrs Williams’ was “absolutely fine”(26,3) for Dr
Singh and Mrs Hardwick’s death was “as good as can be expected”(16,4) according to Dr
Young. These hesitant judgements about the deaths of the case-patients were often
qualified by the fact that it had occurred in hospital. The role of place as a moderator
demonstrates the primacy of the acute role of the hospital for staff when considering the
case-patient admissions, and the scope of the contemporary discourse about good deaths
occurring at home, which interviewees broadly ascribed to. The judgements on the
deaths often appeared to be made from the perspective of home care not meeting an
idealised standard, echoing the findings of Thomas et al.[32](see also chapter 6).

5.2 Benefits to the family

The benefits of a hospital death to a case-patients’ family were a key positive mitigating
factor in the assessment by interviewees of patients’ place of death. The following
benefits were recognised in reference to Mrs Saunders by Dr George, ward doctor:

“RG: I think allowing people to have as long as possible of as good quality of life
as possible at home is something that sound, is certainly good. But to say that it’s
intrinsically a bad outcome to have people die in hospital I question. Because I
think culturally having someone die in hospital means that you don’t have the
knowledge that someone’s died in your very house in say a bed or a room,
someone else helps with the paperwork and support for funeral arrangements
and legal issues, you have a chance to get some sleep perhaps and think only
about the person and being with them to support and not physically caring for
them. So I think it’s quite naive and misguided viewpoint to say that quality is
measured by people not dying in hospital.”(5,4-5)

In the following sections, I explore these benefits.

5.3 Carer support

The hospital offered respite to family carers. For Dr George in the quote above, hospital
offered family members the opportunity to focus on the patient as a friend or kin rather
than as a patient for whom they must provide care, as in the home (see also [64, 271,
272]). The respite offered to carers was not necessarily welcomed however. For example,
during his mother’s final admission to hospital, the new status of visitor made Mr Clarkson feel unwanted:

“SH: Were you disappointed that she died in hospital because she wasn’t at home for you to be doing the final...?

DC: Because I could have been there and if she’d been here I could have been there and sort of been with her all the time and obviously in hospital that’s not possible and I think apart from that, I’d got used to her being here so much so I got used to looking after her so, as I said, it just felt funny not being there and not doing anything.”(9,11)

Mr Clarkson’s visitor’s status was probably reinforced by ward visiting times, which he noted in the interview did not coincide with the times that he felt his mother most needed his care, thereby reducing his ability to “look after her”(9,11). The apparent lack of engagement with Mr Clarkson as an ‘expert carer’[273] may have been a missed opportunity in the care of Mrs Clarkson, but it did provide Mr Clarkson a chance, albeit unwelcome, to relinquish some of his caring role.

Prior to the death, the expertise of the hospital was recognised by some to be helpful. Mr Allen felt that Mrs Hardwick’s family appreciated her being in hospital because it meant they were informed of her medical condition and could understand why she was dying. For others, like ambulance interviewee AS Darby, a death in hospital was thought to be reassuring to families that the patient had received sufficient medical treatment, thereby relieving concerns of carer-guilt about whether there was more that could have been done for the patient. Whilst this was not directly echoed in the next-of-kin interviewees, they did appreciate the hospital as a site of specialist care which they felt the patient needed and could not be provided at home, a point I return to below.

5.4 Messy body and memories

Both Mrs Clarkson and Mr Saunders had expressed to their next-of-kin that they had wanted to die in hospital. One benefit was because it would mean that their family would not be burdened with caring for their dead body. Seeing the body was considered unsettling and concerning, as Mrs Saunders recalled; “he said ‘I think it will be awful as well if she came in in the morning, into my bedroom, and found me dead, I don’t want that at all’”(6,13). A hospital death also relieved the family of the task of removing the body, and organising the certifying and registering of the death. Following the death, both next-of-kin and staff interviewees were concerned about the legacy of a home death for surviving family members. Echoing Dr George’s comments, Mr Clarkson stated:
“DC: if you do have somebody dying at home it always then leaves that certain something in the home that a lot of people can’t cope with, I know that I said the room where my dad died, my sister couldn’t go back in the house, she just felt uncomfortable and it took her months to get back into the house after the funeral etcetera and she never felt comfortable there so there is that side of it is the legacy of having a death in the house as opposed to in hospital, yes it’s nice to be there with your loved ones etcetera but it can be very uncomfortable.”(9,14)

5.5 Being poorly: the desirability of home and hospital

The preferences of the patient were rarely articulated by interviewees beyond a presumption that home was where they would want to be, reflecting the dominance of the home discourse outlined in chapter 2 and 3. The accounts of next-of-kin, by contrast, suggest that hospital offered distinct benefits to the patient beyond those outlined above. Like the healthcare staff accounts, these benefits were premised in the view that home was an ideal place of care and reflect the tensions recognised by staff between this and the clinical benefit of hospital. The benefit of hospital recognised by next-of-kin were orientated around the different functions that home and hospital were thought to offer patients and explained the otherwise paradoxical opinion that case-patients were pleased to be in hospital when they died but preferred to be at home. Of his mother’s opinion, Mr Clarkson stated:

“SH: Do you know where you mum said she wanted to die? I mean, was that discussed?

DC: Yes, she would actually rather it would have been in hospital because I was here on my own obviously, […]

SH: And did she mind being in hospital, you know, some people really don’t like it or other people are happy to be?

DC: No, she was very pragmatic about it, she knew that she was there for a reason and that it was doing her good so, as I say, she would rather have been home if she could have been but she appreciated the benefits of being in hospital so.”(9,6-7)

A similar account was given by Mrs Saunders:

“SH: Were you happy that [Mr Saunders] could be at home for the last few months?

BS: Yes.

SH: Or would you have preferred him to be…?

BS: No, no, no, I wanted him at home where he felt comfortable. It was alright in hospital though because, as I say, all the staff took to him, you know, they would
always keep popping in and that, but I think when you’re in your own home and your own surroundings it is, it’s nicer.

[...]

SH: Are you pleased that [Mr Saunders] died in hospital, or would you have liked him to have died here [at home]?

No, I was pleased he died in hospital, because I always used to think ‘If you’re ill, hospital is the best place to be, because there you can have all the correct attention and everything that you want’. At home, I mean, I don’t know all that much about the medical service really, apart from I’ve been in hospital about 16 times myself, but I don’t... I couldn’t be a nurse, I would do what I could for him but I don’t know, you know, how well I would be doing it compared with a qualified nurse.”(6,13)

In contrast to the comfort of home, hospital was thought to be less desirable, but it did offer “the correct attention”(6,13) for the case-patients; replacing family care-giving with professional care provision and emphasising that family carers did not perceive themselves to be experts. According to their next-of-kin, home for the patients was where you should be when you were well. By contrast, hospital was the best place to be if you were ill, which Mr Clarkson and Mrs Saunders thought their next-of-kin was at the point of admission.

This perception of hospital as a site of specialist dying care has also been directly reported by patients. MacArtney et al. [274] conducted research with Australian end-of-life patients treated in a hospital inpatient palliative care facility. Whilst this kind of facility was not available at Meadowbridge (the hospital palliative care team was primarily advisory, and did not have responsibility for their own beds, typical of hospital palliative care in England [82]), it demonstrates that being in hospital may be of benefit according to patients themselves. MacArtney et al. [274] found that patients treated there recognised it as a place where every opportunity for care was available, which meant that they and family members could be reassured that everything that could be done was done for their loved one.

The need of these case-patients for hospital provided medical care did not seem to stem from a desire to prolong life, but rather that being in the hospital meant that they would receive the most appropriate care for their dying. The need for hospital was because interviewees were seriously ill, since hospital was recognised to be where seriously ill people are treated, deploying the dominant health-seeking behaviour of UK society ([275] cited in [276]). Whilst equating dying with being seriously ill may reflect the apparent medicalisation of dying [277, 278] it also moderates the concerns about the
reported dangers of the hospital for end-of-life patients for receiving acute care, because it repositions patients as less vulnerable by reinstating them as active choosers of hospital end-of-life care.

Furthermore, the distinction Mr Saunders and Mrs Clarkson made between where it was thought they wanted to be generally, and where they wanted to be when they were ill, may also correspond between their preferences for their place of care (home) and place of death (hospital) (see also [68]). This is important because it means that hospital cannot be necessarily considered inappropriate if a patient had a preferred place of care elsewhere. For Mrs Saunders, her husband dying in hospital was appropriate, just as his care occurring at home when he was ‘well’ was appropriate. Given this analysis, it is useful now to review how staff conceived the admissions of the case-patients.

6 A place for acute care and safety: reframing ‘inappropriate’

The rhetorical power of the hospital as primarily a place for the acutely sick was demonstrated in the binary distinction volunteered by interviewees to describe acceptable hospital deaths. Based on medical need, a death following an acute illness was acceptable, whilst those which were as a result of a chronic condition were not. For example, Mrs O’Sullivan’s A&E doctor, Dr Price, said:

“SH: And looking at the kind of current policy push at the moment, seems to be admissions where people die within three days are deemed undesirable. What do you think about that?

HP: Er, undesirable, I think they fall into two categories; I think they fall into ‘expected deaths’ and ‘unexpected deaths’. So the vast… I wouldn’t know numbers, but the people who come into hospital who are seriously unwell, who you aggressively manage in the hope that you’re going to fix them but they still die within three days I think is entirely appropriate. Patients who have end stage… not even an end-stage diagnosis but an end-of-life age, so very advanced age with a potentially irreversible cause of their decline or a palliative diagnosis, I think undesirable, it’s very difficult. If there was somewhere else that they could go to have symptoms and distress and potential distress managed then that would be appropriate, but if there isn’t somewhere else for that to happen then hospital’s where they need to be, unfortunately. So I think undesirable, undesirable if the alternative was available is how I feel about that.”(13,8)

The problem with this dichotomy is that few of the case-patients seemed to fit neatly into one criteria or another. Mrs Thompson for instance was considered by Dr Price to have “end-stage COPD”(13,4), and thus can be considered an “expected death”(13,8). She was also though an “unexpected death”(13,8), in that the treatment of non-invasive ventilation Dr Price started in A&E involved the “hope that you’re going to fix
them” (13,8), such that Dr Price stated disappointment that “later it was evident that we probably weren’t going to get anywhere, that we’d given her the only chance that we could [...] some of them will get better very quickly” (13,4).

The distinction between “expected” and “unexpected” is also difficult because it relies on knowing in advance if treatment is futile. If Mrs Thompson’s condition had improved and she had been discharged home, perhaps she would have been considered differently. Even with hindsight, staff struggled to define whether patients should have been cared for in hospital, as I outline below. It suggests that whilst there was a recognised framework, which matched with the idea of inappropriate admissions and had been adopted by staff, it fitted poorly with the case-patients’ admissions. Patients were admitted for multiple reasons and the admissions seemed inherently complicated, as Dr Choudhry, who offered a similar dichotomy but distinguished between acutely and chronically ill patients, stated, “it’s hard to sort of be generic about these things” (30,5). Furthermore, as Dr Price noted, these dichotomies about admissions were only effective if patients who were not “appropriate” (13,8) for hospital care, but who needed “to have symptoms and distress and potential distress managed” (13,8) could be cared for elsewhere. It is with this context that it useful to consider in more detail the admissions of the case-patients.

6.1 Appropriate or inappropriate admissions?

Whilst the terms appropriate and inappropriate admissions were recognised by interviewees, few of the case-patient admissions were universally agreed as fitting either category, likely reflecting the multiple roles of the hospital recognised by staff. Only Mr French’s and Mrs Clarkson’s admission was agreed by all to be broadly appropriate and Mrs Tonelli’s admission as inappropriate. There was no distinct relationship between when a patient was admitted (in- or out-of-hours), their diagnosis (dementia, cancer or dementia) or their age (younger versus older patients) and whether their admission was considered appropriate. Likewise there was no link between interviewees’ role (community, hospital or ambulance) and whether they thought patients should have been in hospital.

Instead the ‘appropriateness’ of the admission seemed to depend on the emphasis given by interviewees to potentially available care in the context of the patient’s needs and preferences. Which aspects staff emphasised could result in a different judgement such that, as AS Lunn argued, “two people will have two completely different views” (19,7). The
circumstances described by interviewees to justify a conclusively appropriate admission were mostly framed around the limited alternative options for a patient, the need for patients to receive clinical care, or because family members had sought help. By contrast, admissions considered inappropriate were typically explained by the desirability of patients to be at home, and occasionally by reference to the limited help hospital could offer to patients.

Since these factors were often contradictory because they referred to different time points in the period prior to a patient’s admission, staff often struggled to provide a definitive answer about appropriateness. It was apparent from their accounts that defining an admission as appropriate or otherwise was neither easy to do nor a dichotomous decision. Their difficulty answering this question shows the complexity of hospital admissions and suggests that the terms ‘appropriate’ and ‘avoidable’ are not helpful for categorising the case-patients’ admissions. It is unsurprising that these narrow, binary distinctions could not sum up a patients’ admission, given that the admission was the culmination of social interactions whereby healthcare staff were making decisions with limited information and resources in order to achieve the best they could for the patient. In short, the categories proposed by policy could not encompass the messy, empirical reality of the case-patients’ end-of-life care.

7 Conclusion

Throughout this chapter it is apparent that hospital fulfilled multiple roles for end-of-life patients, and was far more than just a provider of urgent medical care. It is clear that whilst hospital may not have been considered a desirable place of care for case-patients, as a site of death it offered benefits to both patients and carers. This was reflected in the role next-of-kin ascribed to the hospital as a place where the needs of ‘poorly’ patients could be met, a role which helped ameliorate the concern staff sometimes expressed about the case-patients place of death.

The terms ‘appropriate’ and ‘inappropriate’ have only limited explanatory use in context of the case-patients’ admissions. This seemed to be primarily because they made the admissions appear as dichotomous discrete events, when in practice ‘appropriateness’ seemed to be determined by the emphasis interviewees gave to the various conceptions of hospital and the needs that these met for the case-patient.

The chapter raised a number of issues that were not wholly resolved. It was clear that to be able to understand admissions, it is necessary to consider pre-hospital care, which I
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do in the following chapter. The inability of A&E staff to not accept admission of the case-patients suggests that the ambulance service may play an important role, and I explore their work in chapter 7.

The chapter has also identified a number of explicitly sociological ideas drawn from the way in which interviewees attempted to make sense of what was going on, and the discordance within policy. Inherent within the accounts was the assumption that greater planning and more information would resolve the admissions, ideas I explore in the next chapter. These ideas mirror those of the policy emphasis on planning and rationalism, and in the discussion (chapter 8) I take forward these ideas to consider the linear planning approach to end-of-life care, within the Durkheimian context of organic and mechanic organisation, as a way of better understanding the case-patients’ admission to hospital. The multiplicity of roles that the hospital could take allowed both the patients’ admissions to hospital and negatively labelled the patients. To understand the multiple functions of the hospital, I also draw in the discussion on the work of Etzioni [192] and the organisational goals of the hospital. I consider too the practice by interviewees of linking the pejorative labelling of end-of-life hospital admissions with patients themselves, such that staff struggled to create a coherent presentation of the patient and their admission. This essentialism obscured that the patients’ admissions emerged from the situations that patients and healthcare staff found themselves in, wherein hospital protocol, varying degrees of staff competency and the necessity of working with limited information coordinated to make the admission of the case-patients to hospital a necessity. To unravel this further, I look at the idea of ‘good’ and ‘bad’ patients and specifically the work of May and Kelly [279] on psychiatric patients and Strong [280] on alcoholism.
Chapter six

“So, yeah, you’ve got to... you need... to nurse people at home, you need kit and stuff and people.”

GP for Mrs O’Sullivan, Dr Abramson, (28,10)
Chapter 6
Community dying: home, carers, and conversations

In this chapter I move the focus chronologically to before the hospital to understand what care had been like for the case-patients in the community. I begin by considering the empirical reality of home for the case-patients, and find that there was a significant discrepancy for some between this and the ideal promoted by policy and advocated for by many of the interviewees. Domiciliary care often required significant modifications to the home, challenging what home meant for patients and their families. These changes meant patients’ homes gained many features of institutional care, but next-of-kin continued to distinguish between home and hospital, with each place offering distinct advantages which were sought at different points in the case-patients’ dying trajectories.

I consider next the care-giving role, and argue that rather than being the cause of admissions, care-givers in practice absorbed much of the instability involved in end-of-life care, in turn helping to avert admissions. Whilst it was expected by many healthcare staff that families would take on this role, there was a recognition that it was not one that they were often appropriately prepared for.

I conclude by considering preventative measures for avoiding hospital admission identified by interviewees. I find that end-of-life care planning was far from the straightforward panacea suggested by hospital interviewees and policy, but was mired in difficulties associated with initiating discussions, estimating prognosis and communicating plans. Partly as a consequence of this, establishing sufficient community care for the case-patients was very challenging and hospital was considered a critical safety-net when it failed. Care for dying patients in the community was constructed as a perpetual battle to maintain a patient at home, where losing meant an admission to hospital.

1 Being cared for at home

The ‘inappropriateness’ of hospital for end-of-life patients in policy is in part because it is presumed that patients should be dying at home. Home is considered to be an ideal site
of death, offering patients comfort and familiarity [1]. This narrative was also offered by healthcare interviewees, and as shown in the preceding chapter, coloured the judgements of the hospital deaths of the case-patients. However, this account was often interrupted by a recognition that home for patients did not meet this idealised version. In this section I explore various conceptions of home offered by healthcare staff and show that it was often a problematic site of care. I conclude by considering the effect of domiciliary care on what is meant by home, and whilst finding that home and hospital remain distinct for next-of-kin, argue that it necessarily altered how patients’ and carers felt about it, potentially making home less ‘home-like’.

The variation in home conditions described by staff undermines the claim that hospital is inappropriate because deaths at home are necessarily ‘better’, and demonstrates one way that hospital could be considered an acceptable place of death for some case-patients and their families.

1.1 Home is nice

A home death was often described by interviewees as “nice”; comfortable, peaceful, dignified and where family and friends could participate. Staff constructed a hierarchy of place of death that matched that found within policy. Home, hospice, and finally hospital (with care home often absent) were the descending order of desirable and appropriate locations of death. For instance the pastoral worker, Mr Allen, said that “certainly the hospice is better than the hospital and I’m sure the home is better than that”(17,8). This conception presumes a dependency between places of death so that factors associated with one place are scarce in a higher or lower setting. Home is conceptualised around ideas of family and familiarity, whilst the hospital is presented as an absence of these things, as AS Watts showed:

“GW: I think a lot of people would rather die at home in a comfortable, peaceful, calm environment than be in a hospital ward, so I’m quite supportive of leaving people at home where we can and [...] I think it’s far more pleasant for the patient to know that they’re with friends and family in a familiar environment than being in a, stuck in a ward where you’re just in a row of beds somewhere.”(12,6)

Hospital for AS Watts was about isolation (“stuck in a ward”12,6), whilst home was full of companions. Achieving a home death for patients was something sought for by healthcare staff from all occupational roles. Home was desirable even where staff were cautious about whether it could be achieved, such as GP Dr Fraser:
“SF: [...] my personal opinion is that I think people should be able to die at home. Most elderly and terminal patients do not want to die outside their home but I think there is a general fear and lack of confidence by relatives etc., and I don’t think necessarily there would be the resources to manage that. So I think if the resources were in place to help support the family then I do think that that would be a good option.” (10,9)

Dr Fraser was caring for Mrs Thompson, who had been admitted to hospital primarily because the care environment at home was not considered suitable. The concerns Dr Fraser raised are explored in detail next, but even with this experience, she still supported the popular contention that home was “good” (10,9). The prevalence of this view was recognised by staff; GP Dr Jenkins thought that whilst there was a “dogma these days, everybody must die at home” (1,6) he still concluded that it was a desirable aim. Dying at home, was the default reference point for staff such that deaths elsewhere were justified from the perspective of why home was not suitable [32].

1.2 Dying at home can be difficult

Despite the putative desirability of home, statements of support for it were often heavily qualified. Home could be “very scary” (32,4) and was not always thought the best place of care for the case-patients. These conceptions of what dying at home were like were not thought to be necessarily routinely recognised by patients, such that Mr Allen argued: “So you know, I can make that decision [to die at home] but I’ll make in isolation of loads of facts that you know, make a lot of difference. A lot of people can say that that’s their intention, yes it would be nice to but I think your view of that can be romantic. And when the reality comes it may be quite different” (17,8), reflecting Gomes et al.’s [28] distinction between public and patient preferences. This “reality” (17,8) described by interviewees was of the patients’ care needs balanced against the physical space of home and the provision of formal and family carers, each of which I explore below. None were discrete concerns, since ‘problems’ in one area often had consequences for another. Each illustrates the differences between home as an everyday structure and home as a site of death, and by considering the changes that are often necessary to make this transformation, I conclude by reflecting on the potential consequences of this for patient and family carers’ conception of home.

1.2.1 ‘An unsuitable environment’: space, equipment and care

The default preference of home as a site of care for case-patients was overridden by staff where they were concerned the environment did not meet the patient’s needs. For example, talking about Mrs Thompson, AS Watts stated that:
“GW: I mean we obviously try, well certainly I try to take into account patients’ wishes, family wishes, but there are times when it’s just unavoidable to take people into a hospital and I think in this case there was no option, we couldn’t leave her at home really, she was in a rather, well a very unsuitable environment, her family obviously weren’t coping and she was soiled, the bed was absolutely soaked, she was in a tiny room, totally inappropriate for her needs, so it was...” (12,1-2)

Whilst AS Watts expressed later in the interview that he felt hospital was an undesirable site of death, compared to the “unsuitable environment” (12,2) that he had found Mrs Thompson in, it was a better place for her to be cared for than home. One reason for this was because she was “in a tiny room” (12,2). Space was important too for family members, as, Mrs O’Sullivan’s son, Mr O’Sullivan, explained:

“CO: Well especially these days because most homes are pretty small and sort of cramped and a patient sort of needs quite a lot of room around them I think and a lot of disruption to make them comfortable. So if people want to die at home and it’s possible and everybody’s in agreement, it seems fine to me, but it don’t seem as though it would be that practical in most circumstances.” (33,11)

Mr O’Sullivan’s comment of the need for “quite a lot of room” (33,11) for dying patients may be because of the extent of equipment that must be accommodated within the home to allow planned care to occur there. In addition to specific medical equipment, such as oxygen Mrs Thompson needed to store at home for treatment of her COPD symptoms, she may also have had to have fitted in specialist furniture, such as a hospital bed, and aids for movement and hygiene, such as hoists and commodes. The consequence of this could be significant, as Mrs Clarkson’s son, Mr Clarkson, recounted:

“SH: Did you arrange it yourself or was it through the doctors?

DC: It was done through the hospital provisionally because they wouldn’t allow her to come out of hospital the first time without the care package being in place and for example, they’d wanted her to have a bed downstairs and the commode which obviously you can see, would not have been practical and so they said that she could come out of the hospital, I arranged, I got a stair-lift fitted, bought wheelchairs, scooters, all, everything that they said I needed I’d bought, had it in place so that she could come home but still be able to access upstairs.

SH: Wow! Yeah, that’s a lot.

DC: Yeah, it was a lot, two and a half thousand pound for a bloody stair-lift but it had to be done, otherwise, because there was no way that she would have been able to have the commode or anything down here.” (9,9-10)

In addition to the cost, both in time and money, to source these items, their presence changed Mr Clarkson’s home. His front room gained a rise-and-recline chair; his
bathroom, bath steps; his hallway, the stair-lift, whilst throughout his house he made room for pipes for his mother’s oxygen.

The meaning of this equipment on conceptions of what is meant by ‘home’ have been explored by others. It has frequently been reported that medical equipment in the home, despite attempts to hide or disguise it, is in practice often obvious, blurring the distinction between home and hospital (e.g. [63, 64, 281-283]). A hospital bed, as Mr Saunders’ wife found, “takes up twice as much space as an ordinary single bed”(6,12) and meant Mr Clarkson was recommended to reorder his home so Mrs Clarkson could be cared for in the front room which could fit in the bed, a routine suggestion in end-of-life care [284]. However, Exley and Allen [64] report how disconcerting this can be where a room also retained its original function, meaning that “you can sit here and watch Coronation Street, and behind you your wife was dying”(p.2321). Mr Clarkson’s determination to ensure that Mrs Clarkson was cared for in an upstairs room where more privacy could be guaranteed is usefully explored by the idea of public/private distinctions within the home (see for instance, Lawrence (1987) cited in [285]). Mr Clarkson’s front room was the most ‘public’ space of the home, visible to any visitor who entered the hallway. The proposed reorganisation of his home would not only mean that the tangible effects of Mrs Clarkson’s disability would be seen by guests, but would also challenge current Western conceptions of home which centre around ideas of security, privacy and identity [285]. As such, caring for a case-patient at home could fundamentally change the way they and their relatives conceived home.

1.2.2 Care

Dying at home was also challenged by the availability of sufficient domiciliary care. Returning again to AS Watts and Mrs Thompson, AS Watts had transferred Mrs Thompson to hospital because he was concerned about how well her care needs were being met; “she was soiled, the bed was absolutely soaked”(12,2). Mrs Thompson had COPD and dementia and was cared for day-to-day primarily by her husband and daughter. Whilst Mrs Thompson also received professional help, AS Watts concluded that due to significant deteriorations in her health the available provision was insufficient for her to be able to stay at home. The situation she was in transgressed the desirability of home for AS Watts and, since he evaluated the hospital would offer Mrs Thompson a better environment to die in than home, correspondingly reordered the hierarchy of place.
It was not just in the family home where this problem of care and place could arise. Mrs O'Sullivan was admitted to hospital in part because her care needs were not being satisfactorily met in the care home she was living in. Mrs O'Sullivan had dementia and both her GP, Dr Abramson, and her son, Mr O'Sullivan, had expressed concern the home was no longer meeting her needs. Her health was deteriorating, and both Dr Abramson and Mr O'Sullivan had considered moving Mrs O'Sullivan to a nursing home which would provide more care. Before this could occur however, Mrs O'Sullivan developed an infection that was resistant to the oral antibiotic treatment given by her GP. As a consequence, Mrs O'Sullivan was sent to hospital, as her GP Dr Abramson explained:

“CA: In these situations, as in this case, part of the reason I'm sending in is cos I cannot get access to the level of nursing care this person requires, and where actually, I know what's wrong with her, I don't need an investigation. You know, in the best possible world, I'm quite capable of prescribing [Drug A] if necessary, and I don't mind doing it. But it's actually... it's around nursing care arrangements and I think none of us can see an easy solution to that. But whether it's undesirable, I don't know. It's far preferable to having a woman lying in bed in sweat- and urine-soaked sheets... Well, I mean, well... no, because she couldn't mobilise at that point, so... I cannot leave her to die with insufficient care. No, that would be much more undesirable!”(28,11)

Like AS Watts with Mrs Thompson, leaving Mrs O'Sullivan in the residential home was not an option for Dr Abramson. The environment at her care home had become inappropriate and as such, the hospital, through the availability of nursing care, became appropriate.

The problem for Mrs O'Sullivan was the same as for Mrs Thompson, despite the different settings. Neither home nor the residential home delivered nursing care as standard, and if a patient’s care needs could no longer be met, the hospital provided what these settings could not at short notice. Dr Abramson and AS Watts prioritised meeting the care needs of the case-patients, such that it became more important how, rather than where, patients died.

1.3 Family carers at home

1.3.1 Physically caring

Nursing care was considered necessary for case-patients to die in the community, as highlighted above. For those case-patients at home, this was primarily provided by family carers. This was a demanding role, as GP Dr Abramson described:
“CA: And nursing someone who is... is... you know, completely physically dependent, it’s very strenuous, and you need a lot of kit. And... you know, if... it... once someone’s completely bed-bound, you really do need a lot of equipment, and oftentimes you have to move the patient into the living room because you need hoists and things that you’re not gonna be able to get upstairs, and it is... does usually... having people die at home does usually involve hijacking a living room, and people just... even the changes that you have to... you know, it’s... Yeah, it’s just a lot of anxiety and talking down and time, which is the one thing GPs have so little of these days. We like people to die at home, and we do try very hard to organise it as much as we can. But it’s... it’s difficult. I mean, the [Care Team] are amazing. I wish there was about eight times more of them. And there, you know, this practical side of nursing people, you know, mobilising, even moving them safely when they can no longer move themselves... One of the injuries that we always try to avoid is that... When somebody becomes very bed-bound, their relatives will often be tempted to pull them out of bed by pulling on their arms, thereby dislocating shoulders. So you have to... And it’s, it’s so typical. I mean, I went to... I went to visit an elderly couple and found both of them on the floor where they had been, God help them, all that night, because she had been trying to get him out of bed to the loo and he had fallen on top of her, and there they had lain all night long. It was ghastly. So, yeah, you’ve got to... you need... to nurse people at home, you need kit and stuff and people.”

As well as the problems of accommodating equipment and space, GP Dr Abramson’s account outlines the physical requirements of family carers, which has also been recognised by others (e.g. [64]). Even the apparently simple task of moving a bed-bound relative, particularly for an elderly spouse who may not have the physical dexterity or strength to do so, could be difficult to do without harm to either party. Having a dying patient at home presumes that carers can and feel able to do this, and furthermore, want to. Mr O’Sullivan for instance, the son of Mrs O’Sullivan, felt that the scale of her dementia made home an unsuitable environment for her, stating “We couldn’t have handled me mum here. We just, no, physically couldn’t have done it. If she’d had something different, I don’t know”.

### 1.3.2 Symptoms and intimate care: the difficulty of home care

The desirability of patients receiving care at home could be contested if a patient’s health condition was not thought to be appropriately managed at home. This could be because of insufficient carer support at home, as outlined with Mrs Thompson and Mrs O’Sullivan, but also because of the symptoms of the patient. A patient was referred to the hospice for example by GP Dr Jenkins, because “there’s only so much diarrhoea you can really control at home”. The dirt and mess of bodily excretion, normally maintained by the patient, can become challenging in dying. The disintegration of the body becomes more likely, leading to leaking bodies which become the responsibility of those caring for the patient as the patient themselves becomes increasingly disabled.
Whilst bodily leakage may be difficult to deal with in a non-clinical environment, Dr Jenkin’s willingness to admit the patient for hospice care also suggests that the home environment was not considered a suitable site for this kind of care. In doing so, he rehearsed Lawton’s argument [288], who argued that in-patient hospice care was used to sequester dying patients known to the hospice who most contravened the taboo of the unbounded body.

Unsurprisingly, this was not only a problem for trained healthcare staff. Mrs Clarkson’s care was mostly provided by her son; “the only thing that I couldn’t help her with would be obviously her personal hygiene, we had people coming in to help with that”(15,15). It seems likely Mr Clarkson did not do this himself because of a transgression of familial relations, given that he personally provided all other care. Intimate care of a spouse or other family member at an atypical time in the life-course (i.e. not between a parent and young child) has the potential to compromise existing personal relationships and has been found by others to be a significant impediment to both patients and family in home care [32, 64]. Dying at home for the case-patients meant therefore overcoming symbolic barriers for some in addition to those of space, equipment and carer skills.

1.4 Dying at home was possible

Dying at home does of course occur successfully and such patients were not included in this study. However, there was evidence that it could have occurred within the sample of case-patients. Even with significant disability it had been expected that Mrs Hardwick would die at home, although she was admitted shortly before death. Whilst she had dementia and lived alone, significant paid help, funded and arranged by family, together with home adaptations ameliorated the effects of her condition and facilitated her continued residence at her home. When comparing her care to another patient, GP Dr Mackay stated:

“FM: ... [another patient] had a very nice death at home. She just sort of went off her fluids, the appetite decreased and at the end, ah, I think at the end she had an underlying chest infection which had been decided she wouldn’t be treated for and the family were very happy, it was well managed I think (laughs). It’s nice to get a good one isn’t it? Because there’s lots of ones where it hasn’t worked like that but (laughs). So I think that’s probably where we would aim to [for Mrs Hardwick], when there would be a sort of change I think or we think this is the beginning of the terminal decline. This lady [Mrs Hardwick] was still living in her own house, you know she had gardeners, drivers, carers and I think....”(15,4)

It was only Mrs Hardwick’s unanticipated heart condition that led to her admission to hospital and subsequent death there. Mrs Hardwick’s home care demonstrates how the
shortcomings of being cared for at home can be addressed through family support and money, whilst her admission to hospital demonstrates that even with this provision, hospital is still used as an emergency resource when unforeseen and unplanned events occur.

1.4.1 Feeling at home, at home

It seems plausible that if Mrs Hardwick had not had her heart condition that she would have died at her home, as her GP had hoped. However, it is unclear whether home would have felt like ‘home’ to Mrs Hardwick because of the scale of support from others she needed. Just like the inclusion of medical equipment in Mr Clarkson’s home, the presence of support staff has the potential to change what is meant family and patients’ meant by ‘home’. Gott et al. [63] found that healthcare staff, whether treated by family members as guests or strangers, could be an ‘intrusion’ on the sense of home to older people, making them feel uncomfortable in an environment that was expected to feel familiar, whilst Milberg et al. [281] argued the presence of healthcare staff compromised feelings of privacy. Paid carers, as Mrs Hardwick had, have the potential to modify the sense of home further. Mr Clarkson described a subordinate relationship with the staff he employed to care for his mother at home, “I had some problems with the carers, some of them were unreliable and, but I’m not one to sort of say, I’m paying for a service, I expect the service”(9,9). His mother’s dependence on their care meant that whilst “the girls”(9,16) he employed were described warmly for the care they did provide, they occupied an unusual position within the home as neither employees, nor family members, and because of their regular visits, not strangers either [289].

Angus et al. [289] show in their Canadian study of home care recipients that whilst material wealth could preserve some aspects of home that were challenging if care was to be provided there, its meaning was still altered. Like Mrs Hardwick’s care package, they describe practices of wealthy participants to maintain the aesthetics of the home (through improved camouflaging of equipment for example), the maintenance of order and cleanliness (by purchasing additional home help), and overcome home limitations for care (such as reconfiguring the layout of rooms to ensure access), but still concluded that in performing these modifications the sense of ‘home’ had necessarily evolved. For Mrs Hardwick, the consequence of staff at home may have been diminished by prior experience in her lifetime of home-help such that their presence was part of her home experience [285], but her increasing dependence on her “gardeners, drivers, carers”(15,4)
is likely to have changed the relationship she had with them, in turn amending what was meant for her by home.

After death, the meaning of home is likely to change again. In the short term, just as the removal of borrowed equipment can be distressing for the family [64], so is the need to cancel help from care staff who are unaware that their patient has died, as Mrs Saunders was obliged to do; “and they knocked at the door and I said I’m sorry, you’re too late, you know, he died during the night”[6,7]. More broadly, MacArtney et al. [274] found a concern of end-of-life patients was that what had been meant by home could be ‘wrecked’ for those that remained following their death at home (p.7). Mr Clarkson and healthcare staff commented on, for example, the permanent legacy to the family’s sense of home of where a family member died, a finding that is also ubiquitous within the literature (for further discussion see chapter 5, section 5.4).

This is not to dispute the overwhelming reported wish of case-patients to be cared for (if not die) at home, nor to suggest that patient and family conceptions of home could not be positively adapted to encompass the above changes. Both Mrs Saunders and Mr Clarkson, as the next-of-kin interviewees with experience of home care, maintained the distinction between hospital and home as a place of care, and emphasised the desirability for their relatives to stay at home where possible62. Mrs Saunders stated that:

“BS: [...] it’s the same with anybody, comparing hospital with home. Home is the most comfortable place and you do get… it’s not timetabled to have all these things at a certain time, your meal is brought, lunch is brought at 12 o’clock whether you’re feeling hungry or not, where at home you can say ‘Are you ready for your lunch yet?’ ‘Oh no, wait a bit, I’ll have it while the 1 o’clock news is on’ and things like that, which I think is much better. But if you are really poorly then definitely hospital is the place to be.”(6,15)

The association between being “poorly” and dying was first considered in chapter 5 (section 5.5) and contributes to my conclusion that dying was not identified by these next-of-kin (and thus by association their case-patients either) as an event distinct from being severely unwell, and therefore where different health seeking behaviours should apply. In this instance, hospital was advantageous because it provided care, but it was not home. It meant schedules for eating and sleeping, reduced patient autonomy, and fundamentally, less comfort. Whilst there have been national attempts in recent decades to make hospital more home-like, through measures such as lifting visitor restrictions for dying patients, greater opportunity for family carers to be involved in the patient’s
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care and a more ‘homely’ environment through improved interior design, for the next-of-kin their success has been limited to date [64].

1.4.2 The desirability of home

The generalised notion of home reported in policy was very distant from the reality experienced by, for example, Mrs Thompson and her family as they struggled to manage her deteriorating condition. Whilst the use of home as a reference point by healthcare staff implies that home can be a ‘good’ place to die for many patients, the patient-cases described above demonstrate the challenges of dying there, and together with prior experiences gave justification for staff to question the doctrine of home care for dying patients, such as the ward doctor, Dr George: “I don’t think I know enough about how you support a death to happen while at home when you just have say an elderly spouse there” (5,4). The cases also suggest benefits to dying in hospital in terms of nursing provision, and imply there may be additional advantages to family carers, which will be explored in the following section. The problems experienced by case-patients at home imply that the desirability of home as a site of death is vulnerable without a suitable home environment, available family carers, and plentiful community care. Where one of these factors was absent, healthcare staff found achieving a home death difficult, and sometimes unfavourable, for the case-patient.

The combination of these factors meant that what was meant by ‘home’ varied greatly, in contrast to the homogenous, idealised image of home present in many staff accounts and ubiquitous in policy [64]. Some, like Mrs Hardwick’s home seemed to be unproblematic, whilst the proposition of Mrs Thompson remaining in her home caused great concern to healthcare staff. An ‘inappropriate’ environment meant staff felt obliged to arrange the admission of case-patients to hospital so as to ensure a more ‘appropriate’ death.

1.4.3 Revisiting preferences

Despite the “[comfort]” (6,15) of home, Mrs Saunders, Mr Clarkson and Mr O’Sullivan still thought that their relative had died in the right place by being in hospital because their relative was considered to be seriously ill and in these circumstances hospital was thought to be the most appropriate place of care. This suggests that where case-patients wanted to die reflected the needs and wishes of the patient at a particular time [32]. For example, the reference to contributing factors of preferences help explain Mr Saunders’ desire to be in hospital according to his ward doctor, Dr George:
“RG: I do feel the admission was appropriate. I think when someone’s dying their preferences are only, their previous preferences are only one of a number of factors that contribute to deciding what’s right to do for them at the time of any change in condition. And that also includes what their current preferences are and I don’t think he had any objections to going to hospital. So I think it was appropriate.”(5,4)

This rebalancing of needs and desires at the end of life matches the nuances suggested of place of death preferences described in chapter 2. In the cases of Mr Saunders and Mrs Clarkson, the next-of-kin accounts demonstrate that case-patients prioritised care needs and comfort; when they were ‘well’ they wanted to be in comfort at home, but when their care needs could not be met they wanted to be in the hospital despite its potential disadvantages. For other patients, the balance of the advantages and disadvantages of the hospital as against other environments may have been calculated differently. Nurse Jones for instance argued that for COPD patients who were often in hospital, the environment could be homelike, offering familiarity and security. This echoes work by Lowton[290] concerning patients with cystic fibrosis, which found that the hospital offered a ‘home-from-home’ environment for some patients, developed from regular admissions where trusted relationships with hospital staff and a sense of safety and security which was not found in the same way at home. For other participants though in that study, however, the opposite was true and home was where patients wished to die. It is apparent then that ‘home’ care may not necessarily mean for all patients care provided in the physical environment of home [64].

It was also clear that case-patients included the needs of their family in their balancing of preferences for setting. Both Mr Clarkson and Mrs Saunders reported that their deceased loved one’s preferences were explained in terms of their own welfare, with Mrs Clarkson for instance reported to have thought “the last thing she wanted was for anything to happen here in the house when it was just me on my own because me dad died suddenly at home so having been through it once before she decided that she would rather be in hospital”(9,6) (see also chapter 5, section 5.4). This corresponds to nuanced view of preferences discussed in chapter 2, whereby place of death choices reflect the relationships that patients are in and a reflection on what dying in a particular location would have for family [32, 291]. Preferences thus can change what is mean by a location, so that, as the case-patients Mrs Clarkson and Mr Saunders reportedly found, home care can be seen as making the family provide care and cope with the practical aspects of death. Where patients want to die is therefore likely to reflect available care and the patient’s home environment, such that in some circumstances these are not preferences
for either home or for hospital but instead for a certain type of death; one that prioritises pain relief, or comfort, or minimal consequence to family.

2  Caring for the case-patients

Family carers were an essential component of a home environment, facilitating case-patients to die outside the hospital, as demonstrated above. Building on the tasks identified required for family carers in home, here I consider their role from the perspective of the family member and healthcare staff involved in the case-patients' care. In doing so I show first what a demanding role being a family carer was, and second, the essential nature of the role such that when this care failed case-patients were admitted to hospital.

2.1  Comprehensive family care

Caring for a case-patient at home was an extensive role for the family carers according to next-of-kin and healthcare staff accounts. Mrs O’Sullivan’s family, as discussed in detail below, delivered much of her care, and Mr Clarkson and Mrs Saunders both provided significant amounts of care for their next-of-kin, although only Mr Clarkson identified himself as a carer, a typical phenomenon in the literature [292]. This caring role was significant even where they also maintained a paid occupation. A full-time job was fitted around caring for his mother by Mr Clarkson:

“SH: Yeah, and were you caring for your mum at home before that, were you the main carer?
DC: Yes, I was the main carer, yes.
SH: And was there a lot of caring involved or...?
DC: There was because she’d try to do things for herself but wasn’t capable of doing it so I had carers coming in to help her with her personal hygiene but cooking, cleaning, laundry, taking her out to doctor’s appointments, hospital appointments, everything like that.
SH: That was you?
DC: Was all down to me.
SH: And were you working full-time as well?
DC: Yes, oh yes. Mm.
SH: That’s a big commitment.
DC: Oh yeah. Uh huh. Yeah, I was, so it got into a routine, do the housework before you go to work in the morning to make sure everything’s ready, the girls used to come in and do breakfast etcetera. Come home at lunchtime make sure that she had some lunch, luckily I could do that because I work close by and then in the evening come home, make dinner and do what needed to be done.

SH: Yeah, that’s a lot.

DC: But I’m saying, it’s just one of these things that you do though isn’t it?”(9,8)

Whilst Mr Clarkson did not acknowledge the scale of the care he provided, it was apparent that caring for his mum took up most (if not all) of his free time, with even his work lunch-hour spent providing for her needs. His routine, like that of Mrs Saunders, was shaped around ensuring his mother’s care needs were met. Mrs Saunders intimated that she spent little time without her husband, describing how her grief was manifest in the emptiness of their shared home; “and I think the worst thing for me is coming home to an empty house, that’s dreadful, especially the last couple of months he was house-bound you know? I did take him out once or twice, just for a little run in the car but he [...] wasn’t comfortable”(6,9).

There seemed to be little respite for family carers, such that even a change of location only meant a change in tasks. Mrs Saunders described a family holiday in terms of oxygen cylinders; “of course we had to take his oxygen with us everywhere. When went to [...] I had to take these big things with us and put them by his chair, and then carry them up to the bedroom, and even [the dog] she sort of went and had a sniff of them”. Even when family members were temporarily relieved of providing formal care, as when patients went in to hospital, their roles continued. When Mr Saunders was in hospital, Mrs Saunders’ routine involved not only frequent visits to him but also thinking about his immediate future needs “I said ‘if there’s anything you want bringing in just let me know’, change of ‘jamas and all things like that, well I had that all in hand in any case”(6,9). Mrs Saunders also spent time planning Mr Saunders’ future care, such as where he could have rested as the seasons changed; “if we have a nice summer [...] we can put…’ a long beach thing that we put out [...] and he can sit down, lay down in the shade there”(6,5). Carers in this way demonstrated how they spent considerable thinking time on their relative; in worrying, planning and organising future care to meet their needs.

It was this persistent concern about their relative, often manifest through anxiety that seemed as great a commitment for next-of-kin as the devotion of their time. Mr Clarkson’s concerns were about needing more support; not for himself but to ensure his
mother was receiving appropriate care. He was uncertain, for instance, about whether he was correctly maintaining his mother’s oxygen supply, exacerbated by the limited help that he received from healthcare staff, especially compared to the advice he had received as a dog owner; “the vet makes sure that everything’s going great [...] puppy dog gets his injections properly but nobody ever made sure that mum was getting her oxygen correctly”(9,17). Mrs Thompson’s family were so concerned about her that they would watch her as she slept to ensure that she did not leave her bed, according to Nurse Jones. These pressures were also experienced by those whose relatives lived in a residential home. Mr O’Sullivan had spent significant time trying to resolve his mother’s care needs: researching suitable homes, arranging her assessment for care funding, and, following her admissions to hospital, negotiating with her then current care home and the hospital about an appropriate discharge for her.

Despite this, no next-of-kin expressed resentment about providing care. Mr Clarkson’s explanation for providing care: “because it’s just one of these things that you do”(9,8) later in the interview expanded to encompass familial responsibility, fitted with the experience of other family members interviewed. However, providing care to a family member was not necessarily easy precisely because of the familial relationship, whereby illness could highlight existing relational strains. Some insight into this is provided by Mr Saunders’ GP, Dr Chapman:

“GC: [...] and obviously the other thing we were very aware of was his anxiety and his frustration. He was fit, having been physically quite a fit man, he was, you know, scunnered and he was getting very annoyed by that, and I don’t think he took it out on his wife but his wife was certainly aware that he was maybe not the easiest individual to live with when he was a bit upset at times.”(04,2)

Dr Chapman’s comments on the role of personality in providing care to Mr Saunders was, perhaps surprisingly, uncommon across the dataset. This likely reflects an undiscussed topic in the interview more than the absence of similar difficulties, given that terminal illness is recognised to have a potential significant impact to patients’ and family care-givers psychological well-being [293]. Interviewees did however, identify the general burden of care-giving to family carers. All the community staff involved in Mrs Thompson’s care commented on the physical toll experienced by her family in caring for her, whilst staff expressed concern about how well Mrs Brett’s partner would cope with providing care for her if she had not been admitted to hospital, given her significant deterioration and associated disability.
These experiences correspond with other family carer accounts. McNamara and Rosenwax [294] found the majority of family carers they surveyed to be involved in hands-on-care in the last few months of life of their relative’s life, as well as assisting with medications and attending medical and appointments. As Mr Clarkson described, the responsibility of the latter could be a source of anxiety “I used to go to every appointment with a note pad and pen, [...] so that when I spoke to the girls and when I spoke to mum I knew exactly what the doctor had said and that the information that I was giving them was correct so’s that there was no misinformation passed on and no mistakes”[9,16]. Recognised characteristics of caring for a dying relative at home include subsuming ones’ routine to the needs of the dying and feeling isolated and homebound [283]. Caring also meant significant financial contributions, whether through direct costs as Mr Clarkson experienced in purchasing equipment, or indirectly such as through the need to leave or reduce hours in paid employment [283, 295]. Like Mrs Saunders found, spouses often end up in separate beds due to the patient’s care needs (“they got a hospital bed for him and he came [home] and had one of the rooms with the bed”[6,2]) resulting in changes to familial relationships and potential carer sadness about the ‘loss’ of a partner [295].

The effects on family carer health and wellbeing have been found, unsurprisingly, to be substantial, studies finding carers deficient in rest, sleep, nutrition, social contact [296], with consequential effects on both their physical and mental wellbeing [295]. Carers are reported to have problems with depression, exhaustion and stress [297], and the demands on carers means that a small minority are unlikely to volunteer to care again [298]. At the same time, studies also report benefits to caring: strengthened bonds between family members [283], a satisfaction of being able to provide for their relative, and often to fulfil their wish to die at home [296]. There is contradictory evidence on the advantages to the grieving process [299].

These studies help to contextualise the experiences of the family carers such as Mr Clarkson and Mrs Saunders, who, perhaps because caring for their relative was “just one of these things that you do”[9,8] did not discuss the difficulties they may have experienced in fulfilling their ascribed caring role. The extent of their role, made apparent from their accounts and the existing literature, makes it clear that their care was fundamental for enabling Mr Saunders and Mrs Clarkson to be cared for at home. And yet both case-patients ended up in hospital, admitted, together with Mrs Thompson,
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Mrs Hardwick, Mrs Brett and Mr French, from their own homes. In the next section I explore in detail the possible reasons for their admission.

2.2 The capability of family carers
In contrast to rare references of families who were “sanguine”(28,9) and needed little outside support, staff from all settings gave accounts of family carers distressed by caring for a relative. Staff talked of families who “begged”(21,8) not to have a patient discharged in case they would be unable to care for the patient: families who “panic or something and they’ll call an ambulance”(20,9) and “anxious relatives who feel they can’t cope”(29,5). This is a persistent trope in the end-of-life care literature, encapsulated in the idea that family carers’ ‘panic’ triggers patients’ admissions to hospital (for further discussion see chapter 2, section 2.3.1). Here I explore the viability of this for the case-patients, by focusing initially on the care of Mrs Thompson before exploring more generally the role of carers in facilitating home care.

2.2.1 The case of Mrs Thompson: when caring fails
Descriptions of Mrs Thompson’s family care provision fitted well into the ‘panic’ discourse. Mrs Thompson had COPD, and undiagnosed but suspected symptoms of dementia. She was cared for at home primarily by her family, with conflicting accounts as to the scale of formal nursing provision (versions differed as to whether she received twice-daily, or no additional community support). As her symptoms deteriorated, the role of her partner and daughter became more essential, such that prior to her final hospital admission they were providing care day and night, as the specialist nurse, Nurse Jones recounted:

“SH: So they were, you think they were doing it all themselves?
AJ: They were doing it all themselves. The daughter was living there and she was doing, getting up in the night and she’d had a fall out of bed and, you know, she’d got a bruise on her face when I went. There were various sort of things that had happened and they’d got some, they’d got like, they were waiting for a mat from the OT, they said they’d get them a mat so that if she got out of bed in the night, they’d hear it because it had got like an alarm and then they could go in because... and that never happened, I don’t think, because they never got the mat, so they didn’t know when she was getting up and it ended up where I think her partner, or husband or whatever, was sat in a chair with her and sitting there watching for her to get out of bed. Her daughter was tucking her in like a baby so she couldn’t get out of bed. It was just...

SH: Not a lot of support.
AJ: No, and the daughter just looked so, so tired. I don't even know if she was sat... she was sort of sat in her pyjamas when I went and she was like, looking like she was falling asleep in the chair because she just looked so drained. And I, I mean, maybe with a bit more... they was saying to me about her going into, maybe a home.”(11,3-4)

This continual care provided by the family and the work-arounds they had devised to keep Mrs Thompson safe were not enough for AS Watts, the ambulance staff called to her, who found her in a situation he thought so untenable that he took her to hospital. Mrs Thompson was not receiving appropriate care, and coupled with her home environment described previously meant that he felt the best way to fulfil his professional duty was to take her to hospital.

Despite the conclusion of Mrs Thompson’s care with death in hospital following that admission, it was apparent that her family were providing indispensable support, which if they had stopped providing would have required replacing with substantial home nursing provision, or if unavailable, to moving her to a facility where this could be provided, such as a nursing home. In practice, her family was keeping her at home and out of the hospital. As her care needs increased, or perhaps as a result of an accumulation of her care needs, it was apparent that Mrs Thompson’s family had difficulty in maintaining an acceptable standard of care - according to the healthcare staff involved - for her, her home, or themselves (note for instance Nurse Jones’ comments about Mrs Thompson’s daughter wearing pyjamas). Interviewees recognised this as partly a failure of the family, and from this made a judgement on their will to care. The locum GP, Dr Fraser, for instance stated that “I just think the family did not want to nurse her to her death”(10,5). Whilst staff acknowledged that Mrs Thompson had received insufficient nursing care and the family had been insufficiently prepared for their role, there was a presumption that Mrs Thompson’s family would provide care. This moral imperative of family to provide care to ill relatives was also recognised by GP Dr Chapman. The doctor’s concern about burdening his relatives with his own end-of-life care was significant enough to outweigh his “horror”(4,10) of dying in hospital to make him consider dying there, and Dr Chapman stated:

“GC: Actually I don’t know where I’d want to die if you asked me. I mean if I was terminally ill, whether it be, you know, say I was Mr [Saunders] and I had my lung cancer... Yeah, I don’t know. I really don’t know because things have changed, hospitals have changed alright? Society’s changed, but I wouldn’t want to impose on my family who’ve got better things to do with their lives rather than look after me as I gradually drown in my own juices from my pleural effusion.”(4,10)
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Dr Chapman’s expectation that his family would feel obliged to care for him unless he facilitated an alternative place of death to home demonstrates the critical and expected role family carers play in supporting the policy aspirations to increase the proportion of patients being cared for, and dying, at home (e.g. [300] and for discussion see [64]). Without the care of family members it seems likely that Mr Saunders, Mr French, Mrs Thompson and Mrs O’Sullivan could not have been cared for at home for as long as they did. Therefore it seems useful to reframe the problem not of families being unable to cope, which maintains this presumption of care, to a question of how families, like Mrs Thompson’s, managed to keep patients at home for as long as they did. This position aligns with the argument later in the chapter about the precarious position patients at home were in, which could easily become unbalanced and if not quickly resolved resulted in an admission to hospital. It seems likely that family carers absorbed much of this instability prior to the admission; Mrs Thompson for instance had been acutely ill for some time prior to her final admission. As a consequence though, it meant that when family exceeded their capacity to care, hospital became the inevitable next destination, acting as the ultimate safety-net.

2.2.2 Knowledgeable carers

The extent of the caring role for family carers is also demonstrated by interviewees’ views that family carers needed to be taught about the dying process. Insufficient awareness of what dying looked like was presumed to have a negative consequence on the care they could provide, and critically how well they could ‘cope’. For example Mrs Thompson’s ward doctor Dr Khan explained:

“MK: [...] So it does seem that we had talked about end-of-life care but we probably didn’t talk about preferred place of care or maybe the family weren’t prepared well enough for the last stages of her dying to manage with the support that we gave and my inclination, without reading the previous discharge, but knowing that fact that Macmillan nursing support was involved is it’s the latter, the family weren’t prepared for the last stages of dying and coping with that and that’s, I think becoming an evident problem because she’s probably the first person her children are seeing dying in close quarters.

SH: Yes, and that’s...

MK: And that’s actually unsettling.”(14,1)

Dr Khan suggests the family needed to be given support to be “prepared”(14,1), and as such he acknowledged that adopting this caring role is not one that necessarily comes
intuitively to family carers. The consequence of insufficient preparation could mean hospital admission, as Nurse Jones argued:

“SH: What would have been needed to keep [Mrs Thompson] at home? Or do you think, in some way, it was just going to happen that she was going to come in?

AJ: I think because the family didn't seem to understand, I don't think they understood how much work it would be, I don't think they understand, or they understood, maybe, how it would, I don't know, you see, I don't know what [my Manager] actually said to them because, in a way, they need to be fully informed of, in a way, in the process of what will happen and, to be honest, her dying from carbon dioxide would have been quite a nice peaceful death because they just go to sleep, and they sleep, and that’s it.”(11,3)

Nurse Jones believed that if her manager had explained to Mrs Thompson’s family thoroughly what the last phase of her illness would be like when she had visited them earlier, and if GP Fraser had known that Mrs Thompson was in the last phase of her illness and would shortly die and explained this to them when they telephoned prior to her admission, the family would have decided to continue to nurse her at home. It can never be known what would have enabled Mrs Thompson to die at home, and other interviewees like AS Watts were reticent about whether it would have been desirable for Mrs Thompson to have stayed at home without professional support. However, the argument of prepared and aware relatives was common across the cases. Patients’ apparent lack of awareness of the dying process was commonly attributed to a general misrepresentation of dying in contemporary society, and especially in the media. The consequential loss of “the art of attending death beds”(28,10) was considered to be a detriment the patient’s home care and to the resilience of family carers and their ability to cope. It suggests that the caring role really was a ‘role’ which had to be learnt, and if taken on by family was a significant task.

The importance of the caring ‘role’ and of families being appropriately prepared for it, has been found by others too. Jack and O’Brien [301] recounted the perception of community nursing staff that some family carers have ‘lost’ the ‘ability’ to care for dying relatives in comparison to previous generations, whilst policy states that family carers require information and support [1]. Family carers have also been reported as feeling concerned about what to expect in the time before a patient’s death, especially about being ‘under-prepared’ for what caring for a dying relative would be like because it did not match the idealised notion of death found in the media [302-304]. These conclusions underline the difficult task caring may have been for the family carers of case-patients and emphasises the significance of their role for facilitating home deaths.
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2.2.3 Conclusion

The care of Mrs Thompson demonstrates one reality of what end-of-life home care can be like, and the significant demands placed on the patient and their family. Mrs Thompson’s reliance on her family for care was partly because of problems in formal support, which were thwarted by issues in communication and changing personnel, as explored below.

3 Preventing an admission

Discussion by healthcare professional interviewees about the prevention of the admission of case-patients was often centred on greater preparation for their death by community staff. In the next section, I explore this contention by considering in turn end-of-life conversations, planning and instigating care for the case-patients. Whilst in practice these measures were interlaced, separating them allows for an in-depth consideration of the challenges community staff faced in preventing an admission. I conclude by considering the utility of these for understanding the case-patients’ admissions.

3.1 Talking about dying

End-of-life care conversations involved decisions about how and where the patient wanted to be cared for, what treatment they wanted and the extent of informal carer support according to the interviewees, a conception broadly in line with policy (see chapter 3, section 1.2.1). These conversations were framed as an important preventative device in hospital admissions by many of the hospital and ambulance staff, including ward doctor Dr Hennessy. Whilst he felt that Mr French’s admission would still be appropriate, the absence of an end-of-life conversation was an important aspect in Dr Hennessy’s judgement:

“SH: So we’ve again touched on this but do you think, from your point of view do you think the admission was appropriate?

PH: From my point of view, yes, but that’s with only limited knowledge of what he was like beforehand, yeah, so I do, I think, again from, I’m kind of second guessing slightly but unless there had been some discussion between him and his family and his doctor, his GP, as to that there was, he was near the end of his life and some discussion around that, I think when people are suddenly forced into that acute setting then they, there’s no other option but bring them to hospital, so I yeah, I kind of can only half answer that because I don’t really know what his circumstances were.”(21,5)
Dr Hennessy portrays end-of-life conversations as a powerful device in preventing admissions; in situations “*when people are suddenly forced into that acute setting*”(21,5) he suggests prior discussions can resolve the issue where otherwise “*there’s no other option but bring them to hospital*”(21,5), a recurrent issue that I tackle in depth in the following chapter. Dr Hennessy’s comments suggests that “*some discussion*”(21,5) in the community is an expected part of end-of-life care for him, but his recognition that it may not have occurred suggests that it could be difficult to achieve. In the next section I explore the problems staff from both community and acute settings cited about initiating the conversations; communicating with patients; and prognosticating when a patient would die. As a consequence, I argue that conversations with case-patients were not routinely held in a way that would facilitate preventing admissions.

### 3.1.1 Timing talk

Working out an appropriate time to have conversations about end-of-life care was difficult. Mrs Hardwick provides a useful example of this. She had dementia, but despite this end-of-life discussions had not occurred as her GP Dr Mackay explained:

“SH: questions about her preferences for place of care and place of death, were they explored or?

*FM: No, I mean to be honest she wasn’t, as I say, we weren’t expecting her to... she wasn’t that ill the last time we saw her so no, I mean we do do that routinely with patients when we think they’re about to go but she certainly wasn’t at that stage and she was just coming for a routine dementia review so I think it probably would have been a bit inappropriate in that situation when she was still getting out and about, being able to go up to clinic sort of two weeks beforehand and telling them whether she wanted eye surgery or not, you know, so (laughs) I think, yes, it just didn’t seem appropriate I think looking at the notes, there didn’t seem to be a time when that was appropriate.”(15,3-4)

Dr Mackay presents here a paradox in the timing of discussions. Having one too early “*would have been a bit inappropriate*”(15,3-4), but if she waited until Mrs Hardwick’s dementia was advanced she would be unlikely to be able to elicit her preferences, a well-recognised problem in the literature (e.g.[305, 306]). As a consequence, when Mrs Hardwick was admitted to hospital following her acute illness, there was no prior recorded decision-making about end-of-life care.

There were other reasons too why conversations were not instigated. For Mrs Brett, the problem of timing was due to the newness of her diagnosis. As her GP, Dr Jenkins explained “*it was all moving terribly fast, I don’t think we’d actually got into any*
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terminal care phase yet with her, we hadn’t had those conversations even”(1,2). For Mrs Clarkson, the unpredictability of her COPD was thought to be a reason why they had not occurred, according to her son Mr Clarkson; “there wasn’t really any long-term discussions at all, it was well just take it and see how it goes was basically one conversation”(9,16), whilst for Mrs Hardwick the problem was that Dr Mackay rarely saw her to instigate the conversation. There could be practical difficulties too, as Nurse Jones involved in Mrs Thompson’s care explained “I didn’t get chance to explain it the second time because when I went, it was very much, they were that tired I don’t think they’d have took it in, to be honest”(11,3). Other studies have shown how patients’ presumed reluctance to discuss the topic, concerns about crushing hope if palliative care is discussed and, where relevant, uncertainty of the disease trajectory are effective barriers for healthcare staff not to initiate these conversations [307, 308].

3.1.2 Involving others in talk

Some case-patient conversations were impeded when it became necessary to involve a third-party. Due to the severity of Mrs O’Sullivan’s dementia, her GP, Dr Abramson, had been unable to hold a meaningful end-of-life conversation with her. Instead, advice was unsuccessfully sought from her son by Dr Abramson:

“SH: And did you have a chance to speak to her son?

CA: He, he seemed to be a bit reluctant to get in touch, but I haven’t... It all happened quite acutely. I was sort of... we were moving gently to it. I have a lot of... I have end-of-life discussions with family frequently, and I don’t usually... I try to get it going in a timely way because I don’t like to push. So, I mean, if I... if I’d realised that she was gonna go into that rapid decline, I probably would have been more aggressive about it, but the nicest way to have a discussion is if the family are visiting at [Care Home] and then I can organise to be there at the same time, and then we can meet and chat and then in the course of a conv-, a general conversation then I can bring up what, you know, DNR [Do Not Resusitate] means and what end-of-life care expectations might be.”(28,3-4)

In order to instigate end-of-life care planning, Dr Abramson had to first facilitate family meetings, a problem exacerbated by the speed of Mrs O’Sullivan’s bodily deterioration. It seems likely that for a conversation to have occurred prior to Mrs O’Sullivan’s death, GP Dr Abramson would have had to have compromised her “gently”(28,3-4) approach at broaching the topic with her son Mr O’Sullivan. The difficulty of engaging family and patients in these conversations was also found by Mrs Thompson’s GP Dr Fraser: “the family were resisting basically conversations about terminal care. They were basically not accepting that she was terminal and so those, what I understand was that that
conversation either hadn’t happened or had been sort of, they were in a little bit of denial.”(10,3). This reflects the conclusion from chapter 2 that a substantial minority of patients and their families may not want to consider the process of dying (see also [309, 310]).

3.1.3 Talk of blame

There was often discordance between how conversations were described by staff who had tried to conduct them with case-patients and those who were affected by their absence. When the difficulties of initiating conversations, timing, language and involving family were recognised by staff it helped ameliorate the blame implicit in reference to admissions and ‘missing’ conversations. A ward doctor for Mrs O’Sullivan, Dr Moss, outlined:

“SH: And what do you, thinking back about Mrs [O’Sullivan], what would have needed to have been done to avoid that admission do you think?

JM: I think these things have to be discussed upfront when everyone has a chance to think and, um, as calmly as possible about what, about possible eventualities and that’s really difficult because it requires someone with a really good overview of the patient and it requires difficult conversations with families and it sometimes, and clearly for every patient like Mrs [O’Sullivan] who would need to have that conversation there are going to be other patients who have to have that conversation with the relatives when actually there isn’t, you know, we can’t predict with 100% certainty who’s going to die next week. And so really challenging I think for the people out in the community to be proactively identifying patients and their families with who these conversations need to be had and of course you can’t just have one conversation, but these conversations need to be had over a number of times. for Mrs [O’Sullivan] it would have required family and presumably GP to have thought and reflected on the fact that she was reaching the end of her life and and have discussed with her what she would want in the event of her becoming very unwell. [...]I sometimes think there’s no choice but to bring a patient to hospital.”(31, 5-6)

Comments such as these, which were typical of more senior hospital staff, accord with current knowledge of these conversations, which suggests that for patients and their families’ end-of-life care conversations are multi-faceted. As established in reference to preferences for place of death, conversations involve consideration of multiple viewpoints, including predicting the availability of future care, family members caring capability and speculating what family members want both for themselves and the patient (e.g. [17, 311]). This conception provides further explanation for why end-of-life care conversations, despite recognised to be important by staff, were not universal in the care of the case-patients.
3.1.4 Accurate conversations

Significant challenges faced community staff in establishing and then facilitating these conversations, which in some cases were enough to mean they were not held. Even where they were, it did not mean that all the patient wishes were accurately known by both parties, as demonstrated by Mr Saunders’ preferences for place of death. He had discussed his end-of-life care wishes with his GP, Dr Chapman, who stated that “we were looking at keeping him at home and discussed things and he was determined that’s what he wanted and, you know, sadly it didn’t happen”(4,7). Mr Saunders, by contrast, was reported to want to be at home until he was dying, when he would want to be in hospital, according to his wife Mrs Saunders. The contrasting views of GP Dr Chapman and Mrs Saunders suggest first the influence of the home death rhetoric whereby Mr Saunders’ conflicting preferences may not have been elicited, but second, that even when these conversations were held, they did not necessarily wholly reflect the wishes of the patient regardless of the skill of the professional, because end-of-life preferences are nuanced and involve multiple, often contradictory, wishes. This, together with the problems outlined above, challenges the utility expressed by some hospital staff in the preventative ability of conversations for ‘inappropriate’ hospital admissions.

3.2 Planning and dying

Whilst end-of-life care conversations were discussed as a key component in preventing hospital, it was the output of these conversations that provided the tangible resources which were thought to prevent case-patients’ admissions. Planning was about the act of turning preferences and choices into a formalised decision for future care. A plan also had a useful symbolic value as official recognition that a patient was considered to be approaching the end of their life. For hospital staff this supported decision-making to not initiate or continue active or aggressive treatment, whilst for ambulance staff it provided documentation necessary to consider keeping a patient at home, a point I explore in chapter 7.

In this section I explore how planning occurred for the case-patients and argue that in practice plans were unstable tools, easily becoming redundant if a patients’ condition deviated from the predictable, therefore moderating their effect at preventing hospital admissions.
3.2.1 The plan in practice

The absence of a plan, as with end-of-life conversations, was used by interviewees to explain, and often challenge admission, as ward doctor Dr Cook demonstrated:

JC: I certainly think there are some situations where people come in and they are probably... they shouldn't have come in. They perhaps didn't want to come in and somehow they've come in. And that... But I don't... you know, I don't think she was one of those in a way. [...] It, it really, depends on whether or not there have been conversations and plans in place before they come in as to whether they're sort of desirable or not in a way, because you know, you have to kind of... to some extent you have to kind of bring people in if they're unwell, but unless... but if GPs and families and patients and hospital doctors already have made plans for them to try and not bring them in, then it doesn't seem like it's great when you do get them in.”(7,8-9)

Her comments echo those of Dr Hennessy earlier. Dr Cook was uncertain whether Mrs Clarkson should (or should not) have been in hospital, but planning was an important factor in deciding this. In particular, those who had had a plan made about their end-of-life care “it doesn't seem like it's great when you do get them in”(7,9), whereby the plan was used to signal end-of-life status and thus broadly to denote unsuitability for hospital care.

It is therefore useful to compare a hospital and community account of planning to understand the utility of planning better. One of Mrs O’Sullivan’s ward doctors, Dr Choudhry stated:

“PC: Obviously she was unwell and she had a chest infection and, yes, we can treat that with intravenous antibiotics, but maybe there should have been clear plan that she wasn't going to be given that and she should have just stayed in the residential home. But it's hard to know without knowing the exact details.

SH: Yeah. But from your... from what you do know and from your perspective only, do you think it was appropriate?

PC: Do you know... Not really. She should have been managed as a palliative patient in the home.

SH: What would have needed to have happened for that to... for her not to have come into hospital?

PC: A clear plan. So a clear plan for the staff in the residential home, for the son, for the GP, for the hospital.”(30,3)

However, Mrs O’Sullivan’s GP, Dr Abramson, noted that:
“CA: And then when I came to see her on the day when the staff said that we were no longer even able to get liquid antibiotics into her, we had a big discussion about what was gonna happen next. Still no input from son, and neither Intermediate Care or District Nursing had capacity to take her on for another four or five days. And [Nursing Home] simply doesn’t have the capacity to provide that level... end-of-life nursing care, and [Hospice] didn’t have capacity, so... You know, it was one of those situations where she needed... if anything was gonna work, it was gonna have to be intravenous antibiotics, which you know, can be done if you’ve got nursing cover, but there really wasn’t any alternative, so in she went. It was actually kind of helpful. She was so well between these periods of illness I thought a little bit of IV [intravenous] antibiotics might just bring her round, and was kind of kicking myself for not having thrown the towel in a bit sooner. But yeah... it was... it is this... it is this difficulty where, you know, if I’d had... if IV antibiotics could be set up in the community, as we once did, then that would have been... we could have decided that that was the treatment, and if that didn’t work we were doing end-of-life care, but it... I would need so much more resourcing in the community to make that happen. We did used to be able to do IV antibiotics at home.”

The emphasis on planning by hospital interviewee Dr Choudhry was grounded in the presumption that plans would be for home or community care, and that the absence of a recorded plan meant that community staff were in some way not fulfilling their duty towards patients. GP Dr Abramson’s account demonstrates that she also thought it would have been desirable for Mrs O’Sullivan to die in the community had sufficient care been available; so here she and Dr Choudhry were in agreement. However, it was also evident that the lack of a formal plan was not because of evaded duty and that planning had occurred, albeit in a different, and more immediate form.

Dr Abramson and Dr Choudhry’s accounts suggest multiple conceptions of what was meant by end-of-life planning. Dr Choudhry’s “clear plan”(30,3), seems likely to accord with an EOLCS conception of advance-care planning (chapter 3, 1.2.2). Dr Abramson planning for Mrs O’Sullivan was more immediate, and, importantly, included hospital as an option. This in turn demonstrates the limited availability of community provision which I explore below. Next though I consider the admission of case-patients where formal planning as conceptualised by Dr Choudhry had occurred.

3.2.2 Plans and acute needs

The occurrence of planning did not mean that it would have the desired conclusion. Mr Saunders’ end-of-life care had been planned and acted on as his GP, Dr Chapman explained:

“SH: And in terms of support, could there have been anything done to avoid the admission?
Dr Chapman expressed frustration during the interview that Mr Saunders had died in hospital. He was unsure why Mr Saunders had been admitted and blamed himself for insufficiently addressing his symptoms. Mr Saunders had organised his own admission by telephoning the emergency services because he had wanted to die in hospital, according to Mrs Saunders. Both problems with symptom control, in GP Dr Chapman’s account, and changes to expressed preferences, in Mrs Saunders’ account, show that even if a plan was followed faithfully with appropriate care put in place, it could still be vulnerable to unanticipated events and could not guarantee against end-of-life admissions in the way hospital staff described.

3.2.3 Superseded plans

Mrs Thompson’s care demonstrates further the vulnerability of plans to unanticipated events. Mrs Thompson had had her care planned, but because since then her needs had “accelerated”(12,3) and exceeded the care arranged. AS Watts explained that:

“SH: Yeah, so if she’d declined more slowly then perhaps other things could have...”

GW: Obviously these things take time to plan and sort out and I think we find this quite a lot that people have, they’ve started with preferred place of care, do not resuscitate orders, but by the time they actually get instigated the patient’s condition’s deteriorated to such an extent that we have no option but, and, or they haven’t been instigated because of the deterioration of the patient’s condition, it takes time to sort things out, get drug boxes, nursing support at home, sometimes it just takes too long.”(12,4)

For Mrs Thompson, planning was highly precarious, exacerbated by difficulties in prognostication, which is recognised to be especially difficult for patients with conditions such as COPD which involve acute exacerbations (see chapter 4, section 1.4.3.3; [312]). If planning were to prevent admissions, it required effective identification of patient needs as Dr Chapman found, flexible to accommodate future care needs and to be instigated quickly, as AS Watts argued.

3.2.4 Sharing plans

The success of a plan also depended on its successful communication, as Mrs Thompson’s locum GP, Dr Fraser, found:
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“SF: Now there had been talk of palliative care in her discharge notes and she was under the care of the respiratory, community respiratory nurse team as well, but there had been no palliative care input and there was no palliative care plan that I could find in her notes. So I, at that point it was clear that the family were totally, you know, it was clear that the family weren’t able to cope with her being at home in that state and I offered admission because I felt I really didn’t know enough about what was going on.”(10,3)

It is unclear if any plans had been made for Mrs Thompson’s care by her regular GP. The difficulty established above of engaging Mrs Thompson and her family in end-of-life discussions suggests extensive planning had not occurred, whilst mentions of palliative care in the hospital discharge letter noted by Dr Khan, and AS Watt’s comments of regular carers, implies it had. Regardless, the absence of a plan that could be deployed by GP Dr Fraser meant that when Mrs Thompson’s health deteriorated, hospital became the most viable option.

3.2.5 Services and plans

Planning could also be hindered by staff knowledge of healthcare services. Hospital admission was offered to Mrs Thompson because she did not know what other care she could arrange, according to locum GP Dr Fraser:

“SF: So I guess I felt that perhaps I should have done more the previous day to have perhaps put that care plan in place, but I felt that as a locum and with very little experience in palliative care I really didn’t feel that I was the right person I suppose to be doing that. So I think I felt a little bit, um, I felt a bit guilty that perhaps I hadn’t organised that, organised a better plan the day before and yet I actually at the same time don’t actually feel things would have changed. It wouldn’t have necessarily changed anything because I don’t, as far as I understand I don’t think there is that service available where, you know, they would have somebody at home nursing her and I just think the family did not want to nurse her to her death. And that was certainly when I spoke to the doctor who was involved a lot with her care, that was certainly his opinion.”(10,5)

Feeling ignorant about available services meant GP Dr Fraser felt unable to create a valid plan for keeping Mrs Thompson at home. Moreover, it is clear that responsibility for planning is not necessarily presumed to lie with the GP; “I really didn’t feel that I was the right person I suppose to be doing that”(10,5). This may because she was a locum GP, but was also identified as a potential problem by other interviewees as to whose role it was to plan future care for patients, particularly for patients who had been in hospital before for their terminal condition and where there was therefore thought to be opportunity for these discussions. This problem is also found in the literature, and
further demonstrates the complexity of end-of-life care planning, which prevents the measure from being a simple solution to preventing hospital admissions [307].

The availability of services could also hinder instigating plans even when they were conducted by someone knowledgeable of what was available and how to access it. Dr Mackay, Mrs Hardwick’s GP, highlighted this problem when discussing another patient. This patient wanted to die in the hospice, but access to hospice care, as previously highlighted, was limited such that ensuring they could achieve their wish was challenging, as Dr Mackay explained:

*FM:* ... *I mean I think it’s much nicer, personally I think it’s much nicer to have a home death if we can do it properly and certainly that would always be the option that I would project to the patient but we do have patients who do not want to die at home. And if they don’t want to die at home, we had one this week who died in a hospice and it worked out because thankfully we got a bed just in time, in the 12 hours just before she died so she got her wish and she died in a hospice. I think it can be difficult sometimes to make that judgement call that they’re right at the end-of-life, particularly if the family or the patient don’t quite perceive that that’s the point that they’re at. It depends on their diagnosis sometimes, I think with cancer it’s easier because you’re kind of pacing yourself and everyone else is. With something like heart failure or something where people don’t always necessarily think of themselves as terminally ill, it could be a lot harder to say “Actually, you know we’re just going to start the diamorphine and keep you at home”, you know (laughs) so yeah, I think it depends, yeah.” (15, 7)

The difficulty of arranging a hospice bed “in time” (15, 7) for the patient demonstrates the fallibility of planning where resources cannot be preassigned. The mismatch between service organisation and planning may be a consequence of the assumption inherent in end-of-life planning that most patients want to die at home, where this problem is not as pertinent, as discussed in chapter 3. Dr Mackay’s account also points to a second problem in instigating plans, of acknowledging a patient is dying. For Dr Mackay, the “judgement call” (15, 7) that it is appropriate to start an end-of-life plan depended not just on being able to accurately identify that the patient was dying, but also on the preparedness of the family and the patient for this. Dr Mackay’s account suggest that this requires sensitive assessment, thereby demonstrating a subjectivity to plans that was often absent when hospital staff talked about it as a solution to admissions.

### 3.2.6 When planning would not work

Hospital staff, like their community colleagues also recognised that in some circumstances a plan was insufficient for preventing an admission because a patient had been admitted for a condition different from their terminal disease. For ward doctor Dr
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Browning, this made Mrs Clarkson’s admission unavoidable; “even with the best plan in the world, she then had, even if you were looking at her cardiac function and respiratory function, she then had something else that was different and, again, I think you wouldn’t necessarily have guessed from the outset that it would have been not survivable”(8,3).
Planning was also considered superfluous for admission prevention where there was a consensus that the admission was appropriate because patients needed acute care. Both Mrs Brett and Mrs Hardwick’s admissions were broadly considered ‘appropriate’ either because their cause of death was unexpected (Mrs Hardwick from a heart condition) or because it was very rapid (Mrs Brett from a newly diagnosed malignancy). In these circumstances, a suitable plan that would have encompassed this would have to be so broad as to be unspecific, and thus presumably unhelpful. Their conditions were unpredictable, and thus unplannable.

3.2.7 Conclusion
Planning did not prevent the hospital admissions of the case-patients, but that did not mean that the process was not beneficial. Whilst some staff questioned the fairness to patients of planning where it failed to facilitate a patient dying in their preferred place of death, a concern also recognised in the literature [306, 313] and shared by patients [311], planning was broadly recognised by staff to be useful. Existing research shows advance care planning to be of benefit to patients [306]; and in specific settings, such as the hospice to be correlated with lower hospital admissions (e.g. [314]; although there is uncertainty concerning its prevalence and thus effectiveness outside research sites [315]). There is also concern that the emphasis on bureaucracy in advance-care planning can make the process become routinized such that the completion of planning paperwork is prioritised above listening to patients, perhaps explaining why dissonant views such as Mr Saunders’ preference to be in hospital when he died was not known by his GP [316]. It is also recognised that, as staff found with Mrs Thompson, not all patients wish to participate in the planning process, and even if they do, they may not wish it to be formally recorded, making enacting plans difficult [306].

Preventative planning for the case-patients to avoid hospital was a difficult task for staff because it required them to predict symptoms and events that often seemed very unpredictable. Where patients were admitted for reasons attributed to their terminal illness, plans were vulnerable to service provision, miscommunication and unexpected decline in the patient’s condition. The viability of plans seemed only tenuously associated with the provision organised; Mr Saunders’ admission demonstrates that even where
comprehensive care had been organised plans could still not work out. Despite these issues, staff continued to try to arrange community care for the case-patients even if plans became redundant, but often struggled to put in place alternative care. It is to this issue that I turn to next.

### 3.3 Putting the plan into place

#### 3.3.1 Nursing care

The provision of nursing care was considered critical for plans to be initiated, and therefore limited availability of community services significantly affected the case-patients' place of death. Lack of available nursing care was directly attributed to the admission of Mrs Brett, Mrs Thompson and Mrs O’Sullivan, as their GPs explained:

“PJ: I wondered about perhaps keeping [Mrs Brett] at home with some district nurse support and giving her some steroids, unfortunately when I rang the district nurses they were very busy with another cancer patient and there wasn’t a district nurse available to come and help, so I had a chat to the patient and her husband and said, “what do you feel about being admitted?”, and she wasn’t that keen to go up, the husband was quite keen for her to be looked after, he was struggling.”(01,2)

“SF: I felt it would have been more appropriate for [Mrs Thompson] to have stayed at home but to have had obviously a lot, the nursing support if it had been available at home.”(10,5)

“CA: I'm sending in ’cos I cannot get access to the level of nursing care [Mrs O'Sullivan] requires, and where actually, I know what’s wrong with her, I don’t need an investigation.”(28,11)

The community nursing service was highly valued by community interviewees for the case-patients, but there seemed to be insufficient provision to quickly meet demand. Capacity was often measured by interviewees in terms of days; Dr Abramson described their unavailability to care for Mrs O’Sullivan for at least “another four or five days”(28,2). This was considered too long for patients to wait, especially when nursing support was required for the care of patients whose needs had suddenly changed, as identified previously. As a consequence, in each of the above cases, the GPs facilitated hospital admissions. The problem of nursing provision at the end-of-life was also recognised by GP Dr Mackay, who discussed in our interview that even if discharging Mrs Hardwick home from hospital would have been desirable, it would have depended on the provision of nursing staff. Echoing those of her GP colleagues in highlighting both the importance of nursing care, and the limited provision, Dr Mackay said:
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“SH: And one related question, but I suppose slightly different are there is also a push to have more deaths at home and fewer in hospital, how do you view that kind of?

FM: I think it would probably be positive actually, I think overall if you can give someone a good death it’s a huge benefit to not only the patient but to the family. I think a lot of hospital deaths are pretty horrible and I don’t think it’s an ideal place to die by any means. I think the thing that we struggle with in the community is the resources to manage a death, sometimes it can be quite difficult for the District Nurses with short notice depending on what else is on their caseload. Things like hospice, it depends on beds availability and so, it can be quite frustrating, you know what you want to do or you know how you want to manage it and sometimes people do have, you know, difficult symptoms at the end that we have to refer to the hospice, if they don’t have a bed then sometimes it becomes difficult because what do you do? (Laughs) You’re kind of caught between a rock and a hard place really and ah, so yes, but I think it’s a very positive thing to aim towards home deaths, yeah.”

The concern about community nursing provision is widely recognised, attributed to fewer nurses going into the profession and a corresponding increase to the age profile of the nursing population [317, 318]. Dr Mackay’s comments emphasise the inevitability of hospital care if there was insufficient available community-nursing provision and patients and had “difficult symptoms”(15,7). Whilst hospice was recognised as an alternative, community-based, source of care for patients, Dr Mackay comments echo those of GP Dr Abramson in chapter 5 (section 4.2) when she acknowledges its limited availability. Similarly, whilst reflecting on Mr Saunders’ death in hospital, GP Dr Chapman said: “And, you know, you want to be at home or maybe a hospice but I mean hospice beds are so short they don’t have enough beds and understandably it’s probably better to use more, you know, better use of their time and resource to be used for symptom control so that people can get home”(4,5). The unavailability of hospice provision for some of the case-patients underlined the importance of community nursing support for GPs, and the precarious place case-patients were in if they needed more care than had been planned for.

Dr Chapman was the only GP interviewee who did not discuss difficulties in nursing provision. He had arranged daily nursing visits for Mr Saunders, and it is plausible that Mr Saunders had sufficient care to meet his needs, and so accessing additional care for him was not necessary. In part this seems likely because Mr Saunders deterioration seemed to have occurred predictably, but also because Dr Chapman expressed a close and effective relationship with the district nursing team -“I keep in close contact with the duty district nurse”(4,3) evident by a reference to discussions with them following Mr Saunders’ admission as to why he was in hospital. It seems likely that this relationship
will have been beneficial when arranging care for Mr Saunders. For other interviewees, where this relationship was not evident, arranging any additional care seemed difficult.

### 3.3.2 Arranging services

The difficulties of provision already outlined mask the effectiveness of community staff to arrange services. Without this knowledge, arranging community care could become almost impossible, as locum GP Dr Fraser found:

“SH: Yeah, I hadn’t thought of it like that but it is a kind of a fall back, a just in case if everything…?

SF: Because I honestly don’t know where else I would have been able to have sent this lady at such short notice. Now that may be just my inexperience and lack of knowledge of resources but when I asked other people they didn’t feel that there wasn’t, you know, as I said they felt that the only option in that circumstance was hospital. And that to me just, I suppose that’s the, that was the frustrating thing that there was either an option of being at home on your own with the family and no help, or being in hospital basically.”(10,8)

Dr Fraser’s inexperience of the local area matched the difficulties of hospital staff, who also struggled to set up services to facilitate the discharge of the case-patients. Their accounts highlight the importance of this knowledge, which facilitated the instigation of plans by giving staff leverage in negotiating restricted services, such as hospice care, and likely made it easier for staff to gain access to the limited nursing care.

### 3.3.3 Viability of planning

It is apparent that the case-patients’ admissions could not have been readily resolved by the end-of-life planning that had occurred. The accounts of community staff suggest that if planning was to be effective it would have needed to have occurred significantly earlier in the patient’s trajectory for those admissions that were associated with the patients’ primary illness. This was recognised by some staff, such as Mrs O’Sullivan’s ward doctor, Dr Moss:

“SH: And do you the admission, and we’ve talked about whether it was appropriate, do you think it was avoidable?

JM: Um, not at the point at which it happened. In a different parallel universe, possibly but it would have been... but in order for it to have been properly avoided in a safe and caring way it would have required us to rewind the clock, weeks if not months, prior to her admission, not just 48 hours. And I keep using that word ‘safe’ but I think it really is important that we don’t create a culture or an environment where, there’s an expectation that old people in nursing homes don’t
come into hospital because sometimes it’s entirely appropriate that the ambulance gets called.”(31,6-7)

Even with earlier planning though, it seems unlikely to have prevented the admission of some of the case-patients. Planning would still be dependent on patients and healthcare staff having end-of-life conversations in time and resources being available, and being able to accurately predict the dying trajectory of a patient. Any change in a patient’s condition away from that anticipated in the plan, and thus organised for, necessitated additional care being arranged, often at short notice. This appeared to reflect difficulties of prognostication rather than inadequate planning, but either way made admission to hospital almost inevitable.

The emphasis on planning also meant that the death of a case-patient in hospital was sometimes viewed as a failure by community staff. In the same way that hospital staff could be dismissive about the care they had provided for a patient in hospital because they had not died at home (as discussed in chapter 5, section 5.1), so prior community care could be downplayed, as Mr Saunders’ GP, Dr Chapman did:

"GC: you know, we were looking at keeping him at home and discussed things and he was determined that’s what he wanted and, you know, sadly it didn’t happen. But I don’t know why it didn’t happen. I mean obviously we didn’t get it right for whatever reason but, so there you go.”(4,7)

Whilst Dr Chapman acknowledged later in the interview that hospital admissions were sometimes “unavoidable”(4,9), his disappointment that Mr Saunders had been admitted was apparent. However, it was also clear that Dr Chapman had tried numerous ways to resolve Mr Saunders problems before Mr Saunders called for an ambulance. Dr Chapman listed 11 appointments he had had with Mr Saunders in the three months prior to his death in which he had adjusted and amended Mr Saunders’ treatment to meet his changing medical needs. Just like with family carers and the emphasis on ‘not coping’, the focus on absent planning conceals the efforts Dr Chapman and his team had made to care for Mr Saunders and keep him at home. It seems likely that if this had not occurred, Mr Saunders would have been admitted to hospital much sooner.

4 Conclusion

In this chapter I have explored the role of community provision in the admission of case-patients. I found that for several patients being cared for at home was far removed from the ideal aspired to in policy and inherent in assumptions about the desirability of home death. Even for case-patients whose home settings corresponded more closely to this
aspiration, home care had consequences and seemed to alter what was meant by home. I argued that family carers were likely to have delayed or prevented earlier admissions, by absorbing much of the instability of community provision, despite their limited training. To moderate the instability, care planning was recommended for end-of-life patients. Whilst I found that staff were advocates of the process, for many of the case-patients it did not occur. This was not a reflection of staff inaction, but rather the difficulties of instigating end-of-life conversations and arranging appropriate care for patients, particularly where care needs were considered unexpected or unpredictable.

Overall, the care of case-patients in the community appeared to be a continual task of prevention, which if unsuccessful necessarily meant they would have to be admitted to hospital. In this context, hospital was an emergency resource providing essential nursing care for patients. When it provided a solution in this way to patients' insufficient care at home, it became a benevolent and appropriate site of death. In the next chapter I explore the role of the ambulance service, who acted as arbiters to this emergency resource.

As with the previous chapters, there are a number of sociological ideas that I will draw out in the discussion (chapter 8) to develop a greater perspective on end-of-life admissions. To understand the avowed preference for home, despite the impracticality of it as a care space without significant modification, I draw on Giddens [188] work on sedimented practices. To reveal the tensions caused by the difference between the ideal of home and patients' actual home-set up, and with the difficulties community staff had in facilitating home care, I use Giddens [188] structuration theory. Lazarus' [319] coping theory, together with an exploration of Schutz's [320] typifications, help to untangle how family carers managed to care for as long as they did and to understand why they did perhaps eventually 'panic'. As previously, the emphasis on end-of-life planning was pertinent, and I use Burns and Stalker [191] conception of organic and mechanical organisation to consider the difficulty community staff had in facilitating end-of-life care plans.
“yeah, massive repercussions for me, because she didn’t have anything saying that she didn’t want to be resuscitated, she wasn’t quite... she wasn’t dead yet, even though it was obvious and looking at all the medical history and things that she wasn’t gonna make it, and how she was acting. However, there’s too many repercussions. I would lose my job and everything like that to warrant it. Whether it’s the right decision or not is irrelevant really, according to the Ambulance Service. So that’s why we took her in.”
Chapter 7

Gatekeepers to hospital: the ambulance service

Ambulance staff were critical in the admissions of the case-patients, acting as a mediator between the community and the hospital. All of the case-patients, regardless of time of admission, were brought to hospital via the ambulance service. Since A&E staff were reluctant to turn away the dying case-patients (chapter 5), this put the service in a critical role as arbiters of hospital admissions. However ambulance staff were working in challenging situations; they often became involved at the point where community provision was exhausted, where patients were too ill to express their wishes and frequently had very limited patient information to guide decision-making. In these circumstances ambulance crews struggled to keep a patient at home, even if they themselves felt this was in the patient’s best interests.

In this chapter I consider the role of these personnel, beginning by exploring the extent of their discretion to keep a patient at home. Next I consider the role of ambulance ideology of conveying seriously ill patients in hospital and the influence of recent policy changes for ambulance staff to support patients in their homes on the care of the case-patients. Then I explore the working environment of ambulance staff caring for the patients to facilitate keeping a patient at home in terms of patient information and, in the penultimate section, the extent of available community provision. I conclude by assessing the role of out-of-hours provision in the case-patients care, and argue that whilst ambulance staff have a key role they struggle to keep patients at home.

I Limited autonomy

The idea of deciding not to take a case-patient to hospital, and instead leaving them at home was difficult for the ambulance interviewees. For some, it was anathema to their role, especially when a case-patient was considered acutely unwell and where hospital treatment was regarded as a solution to their symptoms or care needs. For others, whilst facilitating a case-patient to stay at home was thought to be a far better conclusion for the patient than taking them into hospital, it carried significant risks to the ambulance interviewee. For all however, keeping a dying patient at home was an uncomfortable
task that they felt little supported to do. Staff\textsuperscript{54} lacked the autonomy to be able to authorise keeping a patient at home, particularly without any EOLC documentation.

The consequences of this were outlined most directly by AS Mitchell who was the ambulance staff caring for Mrs Tonelli together with his crewmate AS Simons. AS Mitchell was aware that Mrs Tonelli was dying and felt that hospital care would be of little advantage to her over remaining in the care home where they had been called to. However, because of the presumed consequences if Mrs Tonelli was ‘left’ her at home, AS Mitchell felt obliged to take her to hospital:

“SH: And what did you think about taking her in? Were you happy to do it, or were you... had reservations or...? 

TM: It’s hard, because we’re supposed to take her in... It was obvious to me and my crew mate at the time that long term she wasn’t gonna see another day, unfortunately. We knew... we’ve done enough to see that there wasn’t anything else to do. However, kind of following protocol and stuff like that... I can’t remember, and I don’t think there was a DNR in place, I can’t remember or not. But no, I don’t think there was actually. No, there wasn’t a DNR in place so we had to take her in. But it was obvious that she wasn’t gonna make it, but because of our protocol we have to kind of just take her in, and I remember taking her into hospital and seeing all the blood work and things, it wasn’t gonna... wasn’t gonna make it. But unfortunately... I don’t agree with it, I personally would have, if I had a choice, left her there and let her just pass. But I can’t. It’s not my... it would come back on me too hard to warrant that.”\textsuperscript{(22,2)}

AS Mitchell’s comments about the potential personal professional consequences of leaving a dying patient at home, clarified later in the interview as losing his job, was not a fear shared by all ambulance staff. AS Simons for example replied to my question asking about possible repercussions for keeping a dying patient at home that as long as “you can justify and you can explain why you’ve done it and you’ve done it for the right reasons you’ll be backed [by the service]”\textsuperscript{(23,4)}. Even AS Simon’s response though implies that staff would be asked to account for ‘unusual’ behaviour and suggests that neither staff member had much discretion to keep Mrs Tonelli at home.

AS Mitchell’s concerns were not unrealistic; AS Watts, who cared for Mrs Thompson, outlined for example how he had had a complaint made against him because he had not taken a dying patient to hospital but had instead left her at home so that she could die in accordance with her preferences. Moreover, AS Mitchell’s hesitations about not conveying a patient to hospital were shared by the other ambulance interviewees. In the situation of a dying patient wishing to stay at home, AS Lunn suggested he would be “seeking probably more clinical advice”\textsuperscript{(19,6)}, AS Darby, when it happened to her, sought
authority from her superior (and subsequently they from theirs), AS Watts, as shown above, kept the patient at home but had to defend himself to his manager, AS Mitchell, as we know, would be worried for his job, AS Simons stated that “you’re never going to get it wrong taking them in” [23, 8] and finally AS Burks thought “we could be in quite a lot of trouble for that” [29, 3] if there was no clear patient directive. Their comments, together with similar concerns from staff reported in the literature (e.g. [323, 324]) suggest a service-wide hesitancy about keeping end-of-life patients at home, a point I explore in detail later. The answers given by staff however, of either seeking permission or being prepared for trouble with their superiors, also imply that it was not wholly about ambulance policy and suggest staff who had limited autonomy to contravene ambulance trust protocol as they perceived it.

AS Watts had managed to keep a patient a home, and he was clear that ambulance staff who acted like AS Mitchell did were considered to be not appropriately prioritising patient care. AS Watts stated:

“SH: Can ambulance; if you have a patient like [Mrs Thompson] who said, someone has made that call but actually the majority view of the family or the patient is actually ‘I want to stay at home’, can you leave someone at home if you’ve been called in?

GW: We can and from a personal point of view I try and respect the patient’s wishes wherever possible, but we have a whole mentality where we just pass the buck if you like, I think a lot of people don’t have the, what’s the word I’m trying to find, the opinions to stand up for the patient’s rights, it’s easier just to take them into hospital, there’s no criticism for taking them into hospital, whereas if you leave them at home and they die there can be potential comeback, which I have been through with a patient who had terminal cancer, I’d been out to see her, she was obviously near her end of life, her husband didn’t accept that she was near her end of life, speaking to the patient I think she knew she was going to die and wanted to stay at home, he didn’t want her, she had a whole package in place, the district nurses were in, end-of-life care, drugs, and she passed away three hours after I’d left her at home in her own bed, where she wanted to be, but I had a complaint made about me because I’d left her at home and not sent her back into hospital.” [12, 5]

Rather than framing AS Mitchell’s decision as a self-interested act as AS Watts did, it is relevant to explore why AS Watts and AS Mitchell did different things. Both recognised that by taking the patient to hospital, staff were abiding by ambulance protocol of identifying ‘time-critical’ patients who need to be quickly transferred to hospital to receive life-saving care [325]. They both also recognised that patients were sometimes taken to hospital as much for the benefit of staff as the patient and that home was an appropriate place of care for dying patients. Their discordance on what to do with
patients in this situation suggests that it may be attributed to how much staff felt they could “stand up for the patient’s rights” (12,5). AS Watts, as a senior member of staff, probably had a greater ability to do this and to act on his professional knowledge than AS Mitchell. That AS Mitchell’s concern was shared by other staff, suggests that it may not be unique to Mrs Tonelli’s care. In the next few sections I explore this, considering the role of surveillance and patient documentation to understand the extent of ambulance discretion in keeping the case-patients at home.

1.1 The control room

Some interviewees, as outlined above, did not share AS Mitchell’s dire view that keeping a dying patient at home would cost them their job. However, their ability to exercise their professional autonomy was still limited in regard keeping a patient at home, as AS Lunn explained:

“SH: Could you then sit with that patient until they died or is that not your role?

NL: I would say that would probably depend on individual circumstances but it would probably be, well it’s tough, yeah I think. You could probably get it as being our role but I think it would be, you’d have to, it would be quite hard to explain that to our control and bits like that I guess. I think we could fight that, you know, we could do that.” (29,5)

For AS Lunn, in this instance staying with a patient was not something he felt empowered to do. To do so would be to challenge accepted practice, which could be done, “we could fight that” (29,5), but the need to do so made it a “tough” (29,5) situation. The role of the “control” (29,5) in this instance seem to be to overtly monitor and indeed ‘control’ behaviour.

Ambulance staff work is allocated by a centralised office, where staff match patients to ambulance crews by proximity and other criteria. This requires that ambulance crews’ location and their availability is monitored. In practice, this makes the control room a controller, not just of patients, but of staff too. McCann et al. [326] explored this in their observational study of ambulance work. They found that the ‘Control’ helped regulate staff behaviour. Journey times and routes were recorded, and on occasion both were commented on by senior observation staff who could make suggestions to ambulance staff on recommended routes or the time staff spent with patients. Satellite navigation meant that it was known when vehicles should arrive at addresses and in this way staff were under continuous surveillance. In these circumstances, it is unsurprising that AS
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Lunn did not feel empowered to keep a patient at home without being prepared to justify his actions.

1.2 Recorded decision-making

Having access to documented aids to decision-making was highly regarded by all ambulance staff interviewed because it directed their action and could legitimise not taking a patient to hospital. AS Simons, for instance, initially thought like AS Mitchell that Mrs Tonelli should have been kept at home. However, the absence of any “pathway or end-of-life stuff”(23,2) to dictate his actions, or any response from Mrs Tonelli meant they did take her to hospital, with AS Simons explaining:

“SH: And can you tell me about Mrs [Tonelli] how you kind of found her and how she was?

GS: So we found her initially in her bed, in her room, she was obviously very, very poorly, just looking at her you could tell she was probably going to pass away that day if not within the next couple of hours, if not within the hour to be honest. And our initial plan would have been to have left her at home, however, chatting to the care staff there was no pathway or end-of-life stuff in place at all. As far as the care staff were concerned this lady was still for resuscitation and there wasn’t a great deal on her medical history but it was apparent that the lady was bedbound and did have quite a poor quality of life and did have dementia. So she wasn’t able to communicate her views at all so and wasn’t really making any verbal commands at all, it was more just grunting and groaning.”(23,2)

Leaving Mrs Tonelli would have meant trying to arrange a GP to visit her, which AS Simons knew from an earlier case in his shift that night had limited capacity, a point I explore later. Taking Mrs Tonelli to hospital was more straightforward than keeping her at the care home and could be easily justified; AS Simons established a little later in the interview that he “wasn’t confident that if we left her the care staff would be able to manage her and keep her comfortable”(23,2). He had little to bolster his confidence without documented care plans. Mrs Tonelli’s inability to communicate her preferences meaningfully also made keeping her at home less likely. Patient preferences were considered important currency for ambulance interviewees, so if available could have provided a counterweight to this concern and could have helped AS Simons to consider keeping her at home. Without either plans or preferences, AS Simons and AS Mitchell decided to take Mrs Tonelli to hospital.

Recorded decision-making even held weight with ambulance staff when it referred to behaviour that was not relevant to a specific situation. Resuscitation orders were
commonly referenced by ambulance staff, as evidence that patients had been formally identified as end-of-life. This gave staff the scope to consider not to take a patient to hospital, as described in the comments about ‘DNRs’ by AS Mitchell:

“SH: And if there wasn’t any formal paper work but you’d come out, it was a family, to like a family home and there was a patient, and they really were like in the dying stages, and they were like, ‘I’m just calling because I just want to make sure everything’s going all right. I’m a bit scared because she’s kind of, she’s not responsive, but she’s not very well.’ Do you think then you would be more comfortable leaving her if the family said that, “We want to keep her here, we don’t want to send her in”?

TM: Unless there’s paper-, I mean, we need paperwork to state that, they need either Living Will so they’ve got Power of Attorney over here, or if there’s DNRs in place as well. I know technically a DNR is only when she’s actually arrested we don’t start, but however if that’s in place, for me anyway, personally, I would start looking at, well, that is in place, doctors are aware that she’s gonna pass, can I speak to an out of hours doctor just to work out a way. However, if that’s not in place then obviously it hasn’t been discussed, and then we’ve got no other choice but to go to hospital. And so no, a family home, unless there’s paperwork saying that that’s what they wanna happen, and then we can entertain it, we can speak to out of hours doctors, but no, without paperwork our hands are tied and we have to do what’s in the best interests of the patient.”(22,5-6)

Resuscitation orders formally only prevent healthcare staff from initiating resuscitation on patients on whom it is decided it would be against their best interests, or where the patient has made a formal request. AS Mitchell’s emphasis on the form was however practical; Murphy-Jones and Timmons [324] found that resuscitation decisions were the most likely documented decisions about end-of-life care found by ambulance staff. The documents provide evidence of senior clinician decision-making, since in the UK clinical responsibility for the order rests with the most senior clinician involved in the patient’s care (either a consultant, GP, or experienced nurse [327]). AS Mitchell’s extension of the scope of this proxy authority beyond the prescribed situation demonstrates the influence of this distant authority whilst also emphasising the limited discretion AS Mitchell felt he had to act on his belief that staying at home was in Mrs Tonelli’s best interests.

Even where there was documented decision-making, it was not always enough for ambulance staff to keep a patient at home, as AS Darby recounted:
“KD: And I had this not that long ago in a care home up in [Place], patient was dementia, she was septic so that’s a big infection that basically spills out of the organ and into the blood and it’s fatal, big high mortality rate. And that patient before she’d become unwell had written in a care plan when she arrived at the home “I do not want to go to hospital for anything other than if I break my hip, you know, I’ll go for something like that, but anything medical I don’t want to go, and if I have cardiac arrest I don’t want to be resuscitated”, and they, she was adamant about that. Two years later this sort of, this happened and the family who had power of attorney and obviously there’s two types, there’s medical power of attorney and there’s property, but we had to make sure, we had to send the patient’s family home to get the actual letter and bring it back and show us. And they also said “we want her to stay here”, even though septic, sepsis is treatable with antibiotics, “she has said I do not want to go in, and if you take her we will sue you”. And, you know, it took us a number of hours, me and a crew with an out of hours GP who refused to come out, and her manager [presumed GP out-of-hours call-handler manager] and her manager and then her manager, so we went four rungs up the ladder, even spoke to our manager, spoke to the clinical support desk, you know, literally we had to get lots of people in just to get really the own way of the patient so it’s quite difficult.” (18,8-9)

AS Darby who was called to care for Mr French, describes a different patient to explain the challenges of not taking a patient to hospital. Her concern was in part due to the fact that the patient’s illness could be resolved at the hospital- “even though septic, sepsis is treatable with antibiotics” (18,9) - a point I take up below. Her reference to a health and welfare legal power of attorney refers to someone legally charged with making decisions on behalf of the patient in accordance with the Mental Capacity Act (2005). What is particularly pertinent is that even with this legal framework, AS Darby and her colleagues still “had to make sure” (18,8) it was legitimate. The effort they were obliged to go to in order to do so and enact the patient’s wishes demonstrates how their professional autonomy was compromised.

It is apparent from these examples that ambulance staff struggled to keep dying patients at home. End-of-life care documentation was used as proxy permission from senior staff from other occupations for them to countenance considering not taking a patient to hospital. This situation helps explain the emphasis others have found ambulance staff place on recorded decision-making [324, 328]. However even documentation was not always sufficient, and AS Darby’s examples demonstrates the need felt by some ambulance staff to gain definitive permission from senior staff within the ambulance service.

1.3 Seeking support

When ambulance staff did deviate from established practice, which keeping a patient at home appeared to be, they often described seeking advice to help resolve the problem.
This was often from community healthcare staff, typically GPs, who could provide authorisation and put in place necessary care, as AS Simons explained:

“GS: We are supposed to find, the thing would have been if we had of left her we would have had to go back through the 111 service to get an out-of-hours GP to come and see her to obviously get this end-of-life pathway activated, do not resuscitate, get the lady comfortable and having already spoken to them that night I knew there was a two hour wait to get a doctor out.”(23,2-3)

Beyond illustrating the difficulty of arranging for a GP to visit Mrs Tonelli, an issue I discuss below, AS Simons’ comment suggests that the involvement of the GP was as much about passing on responsibility for Mrs Tonelli’s care as it was about ensuring her comfort. For AS Simons, leaving Mrs Tonelli at home could only be done if there was someone more senior who could be accountable for her death not occurring in the hospital. The lack of availability of anyone to do this was part of AS Simons’ justification for taking Mrs Tonelli there. That this passing on of patient responsibility is recognised in some ambulance service protocol (e.g. [324]) demonstrates the limited scope ambulance staff have generally in deciding not to convey end-of-life patients to hospital.

In some cases, staff relied on support from within the ambulance service when deciding to whether to not take a patient to hospital. As AS Darby described earlier, the “clinical support desk”(18,9) was one such channel. The service helped staff to gain authorisation to undertake atypical behaviour as AS Lunn explained:

“NL: But I think if we’d had more of a response from them [the family] indicating that, you know, he didn’t want to go [to hospital] or he himself saying he didn’t want to go then I think I’d be seeking probably more clinical advice really from our clinical advice line because, yeah, I think it is a very grey area still. And I think probably I would worry, I don’t know whether other clinicians would, that you are doing the right thing in that situation. Because essentially when you’re looking at someone and they’re time critical and you’re thinking we need to get you treated, we can treat you, or at least the hospital can treat you and we need to, you know, to get that treatment now and start the process going, but yeah it is an odd one really and a tricky one.”(19,6)

His comments emphasise the challenges faced by ambulance staff in treating end-of-life patients with only limited clinical background information, under time pressures and contrary to usual practice for patients who are considered to be seriously unwell, all points I explore later in the chapter. The availability of the clinical advice line in this instance however, whilst clearly valuable to staff, also diminishes staff discretion. AS Lunn describes the advice line as giving reassurance about whether he was “doing the right thing”(19,6), implying that it also acts to authorise (or limit) atypical behaviour just
like the control room, thereby putting restrictions on AS Lunn’s own professional autonomy. AS Lunn’s hesitance about the “grey area”(19,6) of keeping a patient at home also suggests that much ambulance activity is predefined or ‘black and white’ so that staff can act much of the time autonomously within agreed behaviours.

1.4 Solving the problem – more rules

Further evidence of the limited authority the ambulance interviewees had in keeping patients can be found in the idea of more pathways as a solution to problems in ambulance end-of-life care by AS Darby:

“SH: No, because [leaving patients at home] goes against everything?
KD: Yeah. So I don’t see how that’s really going to change. I suppose with things that, if you know something’s terminal then that may be different, so if we start, the government start to bring in policies that say “okay a patient’s suffering from this condition and they don’t want to go to hospital, this is going to be the new pathway for that condition”, not just cancer but other conditions, then maybe that’s, you know, something that the family can discuss and say “actually they do look like they’re about to die, you know, I don’t think we’ve got many more hours or days with them, they have this condition, I’d like you just to follow this pathway now and we want them to stay at home or we want them to go into a hospice” or whatever. And I think that’s going to be the only way forward with that, that it would be for each condition I imagine. Yeah, that’s it really.”(18,10)

By prescribing appropriate behaviour to a given situation, the guidelines AS Darby describes would help resolve the ambiguity for staff in dealing with patients who wish to die at home, although would be unlikely to resolve the complexity of organising care. This desire for prescription could demonstrate that AS Darby was fatalistic about her restricted position because she was not seeking proactive resolutions that granted her greater autonomy. However, this conclusion ignores the challenges faced by ambulance staff. Instead, I would argue that abiding by the ‘rules’ was a rational way to navigate often contradictory guidelines, particularly for staff hindered by limited professional authority.

1.5 Conclusion

The limited authority that made it difficult for ambulance interviewees to keep patients at home may also be found in other aspects of their role. McCann et al. [326] found that if staff did break guidelines, like AS Watts, they tended to be the more experienced staff and justified doing so by referring to the best interests of the patient (similar dynamics can also be seen in hospital resuscitation decisions [329]). Even in these circumstances, staff behaviour still seemed to be highly bound by others’ authority; with staff
knowledgeable about ambulance rules and ready with developed justifications for why they were not abiding by them. They also found examples of staff like AS Mitchell, fearful of litigation and voluntarily recording their own actions and justifications in case they were questioned by management. Overall, ambulance staff were concerned about causing harm to patients and the consequences of not following regulation.

Ambulance staff were hesitant about keeping end-of-life patients out of hospital, especially where there was not documented evidence of a senior decision that could be used as permission. The need for authority suggests that keeping a patient at home contravenes ambulance convention and I turn to this next.

2 Just a ‘transfer medium’

The ethos of the ambulance service was significant for staff deciding whether to take case-patients to hospital. The case-patients were all considered to be both seriously unwell and an emergency, and not taking them to hospital was thought by interviewees to contradict the ethos of the ambulance service. It was this emergency ethos that helped explain AS Mitchell’s concern about his job, AS Watts’ emphasis on end-of-life documentation and AS Lunn’s and AS Darby’s desires to seek further advice. Staff needed permission because their proposed actions to keep case-patients at home appeared to contravene accepted or at least explicit norms. In this section, I explore how this was so, considering the emphasis by interviewees on reversible and acute conditions, time-sensitive requirements and the need to provide care, and their reflections on end-of-life provision within the service.

2.1 ‘Not dead yet’

2.1.1 Treatable

The opportunity to resolve a patient’s acute symptoms was the impetus for much of the ambulance interviewees’ concern, and was realised through an emphasis either on the availability of treatment in the hospital, or the potential ‘reversibility’ of a patient’s condition, and frequently both. For AS Mitchell, the potential for the hospital to treat Mrs Tonelli’s symptoms, even if this would ultimately be futile was the cause for his concern about leaving her at home without authorisation. AS Mitchell stated:

“TM: If I leave someone at home knowing that they’re not very well and more treatment is at hospital, whether it’s gonna work or not, because there is more treatment here, I’m kind of being negligible [sic]. And even though I’ve accepted and I understand, but yeah, it’s not worth my... because I’ll be struck off for
negligence otherwise. So that’s why I think, I don’t think the Ambulance Service as a whole has enough backing for that anyway, but... Yeah, so I think that, that’s why a lot of people do take them in even if they know they’re gonna pass away, just because it’s not worth their jobs, and that’s what we have to do in our little section of remit we’re allowed to do.”(22,4)

For AS Mitchell, hospital was a site of acute care and as a result undesirable for Mrs Tonelli since she was “gonna pass away”(22,4) regardless of the treatment available there, matching the reasoning outlined in chapter 5. However, Mrs Tonelli was also “not very well”(22,4) and so not taking her to hospital would have meant for AS Mitchell that he was reneging on his duties as ambulance personnel, because “more treatment is at hospital”(22,4). Even though this protocol was not something he agreed with, his limited professional discretion meant that he felt obliged to abide by it.

For other interviewees, taking a patient in need to hospital was a more acceptable option than AS Mitchell conceived it, but could still lead to problems. AS Lunn, who with AS Darby was caring for Mr French, felt it had been appropriate to take Mr French to hospital because he had a condition that AS Lunn deemed reversible. Thinking about what he would do if this conclusion conflicted with a patient’s wishes, AS Lunn explained:

“SH: I think that’s the kind of assumption behind it is that perhaps if they die within a short amount of time, excluding trauma cases but end-of-life care patients, if they’re going in for just a final admission perhaps that could have been done at home or rather than I... rather than the admission being avoidable or undesirable perhaps it’s the dying in hospital that’s undesirable, if that makes sense?

NL: Yeah. Yeah. So I think yeah that matters a lot in terms of especially where people have said that they wish to die, and that’s got to be a big consideration for us as well. You know, I think that is a huge thing isn’t it? It’s something you have no control over, you know, that gives you, you know, you are able to say ‘well this is a choice of mine that I would like to be honoured and respected’. And I think, yeah, and I think we’re very much in its infancy as an ambulance service really about doing that because to a degree it flies in the face of seeing something that potentially is reversible and treatable.”(19,9)

For AS Lunn, patient wishes to stay at home challenged his role because they were valued directions, but contradicted what he felt the ambulance service did. Patients like Mr French, who had a symptoms or a condition that was “potentially [...] reversible and treatable”(19,9) should go to hospital. It was not an inaccurate conception; NHS documentation states “Patients will always be taken to hospital when there is a medical need for this”[330], but it does challenge the aims of contemporary end-of-life care which seeks to reduce the medicalisation of dying in part through a reduction of ‘unnecessary’
This echoes concerns from other healthcare occupations about the difficulty of weighing up preserving life and fulfilling end-of-life care priorities (e.g. [105]). AS Lunn’s comment that the ambulance service is “very much in its infancy”(19,9) about this topic demonstrates his conception of a service in transition, a point I explore later along with considering the demanding position this puts staff like AS Lunn in, who must try to navigate these potentially contradictory aims.

2.1.2 Time-critical

For the interviewees the emphasis of the ambulance service was not only on taking patients to treatment, it was also about doing so quickly. For instance, in an earlier quotation the hesitance of abiding by patient wishes if they were contrary to clinical opinion was outlined by AS Lunn: “Because essentially when you’re looking at someone and they’re time critical and you’re thinking we need to get you treated, we can treat you, or at least the hospital can treat you and we need to, you know, to get that treatment now and start the process going”(19,6). The perceived speed at which patients could be treated offered a further advantage over home to patients perceived as in need. Moreover, the emphasis on assessing patients as “time-critical”(19,6) seemed to make leaving patients at home harder because it underlined the responsibility to staff that they were leaving patients to die, something I explore further in the next section.

The stress on urgency was also a disincentive to leave patients at home because it affected how staff prioritised their time. Just like AS Lunn intimated in the earlier quotation with his reference to control and needing to justify his actions if he stayed with a patient, spending ‘too long’ with a patient was thought to be against ambulance protocol according to AS Mitchell:

“SH: Are you bound by how long you spend with a patient?

TM: No, we’re not really bound. I mean, if the paperwork’s in place and we know that... Unless she’s... [mumbled] stay with a patient, but if we know there’s a DNR in place and things we’re gonna ring the out of hours doctors. I don’t know, if there are things in place, yeah, I don’t... it does take too long to get him probably, but we’re not tied down by time as such by the Ambulance Service or anyone else, just how long I feel comfortable being in... But if I think this is all in place and I need to speak to the doctor about some more end-of-life kind of care, then it takes a long time to get hold of a doctor, just sometimes I’ve been waiting an hour/an hour and a half, [...] which is far too long. However, if I could speak to a doctor quite quickly, then it’s absolutely fine and I wouldn’t have a problem waiting on scene to speak to them. In the day it’s not too bad [...]. But out of hours, there’s nothing in place to speak to a doctor quickly. They say they’re run over too many jobs, so sometimes you don’t hear from them for ages, which would
be too long for us really, cos if we wait too long with them then we're starting to get, like I said, negligent again and it could come back on us, which at the end of the day isn't good.”(22,6)

Whilst AS Mitchell did not feel “tied down by time as such by the Ambulance Service” he was clear that spending over an hour with a dying patient was “far too long” and would have consequences to him. The contradiction in AS Mitchell’s answer between not having official time limits and expressing one is likely resolved by his emphasis on his actions; “waiting” for out-of-hours support was unacceptable but, as he explained after the interview, treating a patient could take as much time as he felt was reasonable.

Given that ambulance performance is measured primarily in response time [331], AS Mitchell’s awareness about waiting too long is unsurprising. The consequences though for the case-patients may have been significant, challenging choices to keep a patient at home, even for patients like Mrs Tonelli whom it was recognised were dying and where it was felt that hospital would be of limited benefit. For patients like Mr French it conversely provided further impetus to staff to take them to hospital, because their ‘time-critical’ status meant they immediately needed hospital care, which could not wait for a consultation with a GP or other senior colleague. When care was framed as urgent in this way, not conveying a patient to hospital meant staff could be normatively condemned, as I explore in the next section.

2.2 Abandoning patients

Leaving a patient at home rather than taking them to hospital was equated with neglect by some ambulance staff. To fulfil their duty of care to Mr French, taking him to hospital was the only action AS Darby and AS Lunn considered appropriate. AS Darby explained that:

“KD: if we’d have left him at home, it’s a bit like imagine leaving a child at home that’s got meningitis, you know, you wouldn’t do it. They’ve got something that’s treatable, life threatening but treatable, you’re going to take them in and you’re going to do your best and you’re going to try and turn it all around. And that was really the same with [Mr French].”(18,5)

Bacterial meningitis requires urgent medical treatment as it can be fatal if left untreated [332], so by associating Mr French’s symptoms with this disease AS Darby emphasised the importance of his transfer to hospital. Moreover, not taking Mr French to hospital was equated with an absence of action; of not doing “your best”(18,5). Leaving Mr French at home was to give up on him.
This argument could also be deployed for patients who unlike Mr French, had less immediate care needs and who could also have been conceived as ‘end-of-life’, because conveying them to hospital still meant an opportunity to improve their condition. For instance, reflecting on the patient in the earlier example who had completed an advance directive refusing hospital treatment, AS Darby felt that:

“SH: You were saying about the dementia patient, how you had to go through so many steps in order to keep that patient at home? Is it quite hard if a patient is really ill but they say they don't want to go in, to leave them there? Is that...?

KD: Well it is because it goes against humanity doesn't it? It goes against morals and ethics, you know. There's somebody there that's dying, potentially, you know, they're going to die that day or the next day or even in a week's time of something that you may be able to change. You may be able to reverse or halt or slow down, you know. So if they say they don't want to go then you're like “my god, well you can't say that because that's not right, that's not ethical”, you know, and it's difficult because you want them to go in. You're almost making them go in, you know, but as long as they've got the capacity to consent, or when they did have the capacity they made the necessary legal arrangements, then you can't do anything about it”(18,9)

For AS Darby, being “able to reverse or halt or slow down”(18,9) a patient’s condition was justification enough to want to take the patient to hospital, even though they were probably dying. Her comments demonstrate once more the difficult position staff were in when deciding whether or to not take a patient to hospital when negotiating contradictory principles.

AS Darby’s stance suggests that for some interviewees the end-of-life care ethos of facilitating patient deaths at home was in contradiction to the ambulance service mandate, a finding which aligns with current research (e.g. [306]). Recently there has however been attempts to reform the ambulance service in terms of end-of-life care provision, and I explore this next.
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2.2.1 Ambulance service history

The Bradley report [333] prompted a “quantum culture leap” for the ambulance service, seeking to change the aim of the service from primarily conveying patients to hospital to also providing care in the community where appropriate ([334]p.5). Almost a decade later, the NHS Improving Quality [335] paper on end-of-life care within the ambulance service emphasised the role of the ambulance service as amongst other things to “avoid unwanted hospital admission.” There had only been brief mention of the ambulance service in the 2008 EOLCS in terms of facilitating deaths at home, except the transfer of patients from hospital to home, so the report filled an important gap. With regard to admissions, the report reads as a message of empowerment to ambulance staff to overcome the ambulance ethos of transfer to hospital, as Box 4 outlines.

Box 4 Ambulance policy - ‘Care in the last few days of life’

“To achieve high quality care at this Step [Care in the last few days of life], the role of individual staff is to:

• Act within their scope of clinical practice and exercise sound ethical and clinical judgement to act in accordance with the person’s wishes, insofar as these can be ascertained
• Be prepared to ask on arrival whether a care plan or other statement of preferences or decisions is in place
• Be prepared for the unexpected, including the possibility of differing views or resistance to a person’s care plan among family and carers, and seek further advice where required
• Be willing to be the responsible clinician themselves where appropriate
• Pass on any relevant information gathered about the person’s condition or health status to other organisations involved in their care.” [335] p.26

However, the awareness of this new expanded role for the ambulance interviewees was not clear. The central role of conveyance to hospital remained persistent, as evident by the account of the ambulance staff involved in Mrs Thompson’s admission, AS Watts:

“SH: Yeah, and do you get any say in, can you put it forward to nursing staff where you want her to be admitted to, kind of wards and things like that, or is that not really in your...

GW: That’s a little bit beyond our remit, technically we just take to an A&E, although if there are, if there is an end-of-life package in place and there are preferred place of care and people like Macmillan Nurses or the GPs, district nurses are on-board, we do have a little bit of leeway, the doctors can ask us to take or the district nurses can arrange an alternative place of care, but generally speaking it’s not something that we have much power over.
SH: Yeah, you’re just there to take her...

GW: Transport medium, yeah, sadly, yes.”(12,3-4)

Whilst it is not since 1966 that the ambulance service has solely provided the service of first aid and transfer to hospital [336], this view persists outside of the service too, as demonstrated by a description of ambulance personnel as “ambulance drivers” by the Secretary of State for Health in February 2016 [322]. If AS Watts’ disappointed description of his role as “Transport medium”(12,4) was shared by other interviewees, it provides further explanation of how staff were hindered in their ability to keep patients at home; challenging the default practice of conveying to hospital is difficult if you are unaware that you can do so.

2.2.2 End-of-life care education

Interviewees did however outline how there had been attempts by the service to educate and change practice when caring for end-of-life patients. Whilst recognising the limited role of the service, some staff were however advocating for facilitating home care where possible, as AS Watts shows:

“SH: Yeah. Do you think it’s taboo with the Ambulance Service as well to an extent?

GW: I think it is, I’ve been in the Service for thirty years now and I’ve seen the whole change of things and we do have an end-of-life care package in place but that’s only taught to emergency care practitioners and there are only a tiny fraction of ambulance staff on ECP grades and when you look at the amount of operational staff on the road we, I think we should be teaching this to everybody so that everybody’s aware of the options available to us and what we can do to actually improve people’s end-of-life care which most people in the Ambulance Service would just turn up, do an assessment and take to hospital, they don’t seem to appreciate the individual’s opinions, requirements or desires in any way, shape or form. This is something that I think we fall down on quite badly in the Ambulance Service.”(12,5)

Emergency care practitioners, sometimes referred to as specialist paramedics, are the most senior grade56 of front-line ambulance staff. Since control rooms try to match seniority with patient severity, it can be expected that they will only see a minority of the cases brought to the ambulance service as a whole. Whilst there currently is no accurate recording of ambulance end-of-life care incidence, it is estimated that at least once in every two shifts half of all front-line ambulance staff will see a terminally-ill patient, implying that the majority of staff cared for these patients without advanced training ([336] citing [33]).
AS Watts’ perception of limited ambulance education on end-of-life and palliative care are shared by others (see for example [336, 338]). Whilst both are included in the College of Paramedics’ 2015 Curriculum Guidance, education on it is erratic, particularly for non-specialists [325]. However, even when staff were aware of end-of-life care issues in the ambulance service, as evident in AS Burks’ comments “[ambulance end-of-life care] seems to have got a lot better over the last few years”(29,5), it did not wholly resolve the problem. AS Burks stated:

“RB: And yeah I think it is on the whole quite positive, it can be a bit, we sometimes get called you know, the individual might have wishes to die at home or something like that but when it comes down to it and you know the family get upset and things like that and you know plans can sometimes change, so it would be good to have access to a bit more support then perhaps because it can be quite hard to say “no” to, you know, a lot of anxious relatives who feel they can’t cope with the way things are unfolding. But on the whole I think it’s, it seems to have got a lot better over the last few years.”(29,5)

AS Burks’ remark shows how even when this training was available, acting on it was not necessarily straightforward. Where the preferences of the patient, family members and what is presumed to be best for the patient conflict, “[exercising] sound ethical and clinical judgement to act in accordance with the person’s wishes” could be challenging [335]. These difficulties were not unique to AS Burks’ comments. Others have highlighted these contextual issues which make decision-making more complicated, including dealing with distressed family members, having to work from the patient’s home rather than in a space dedicated to healthcare, and conflict between those present about what is best to do for the patient ([325, 328]). In the following section, I explore further the consequences of these issues of environment.

2.2.3 Conclusion

The comments of the ambulance staff suggest that when caring for the case-patients there was often a mismatch between the aims of the ambulance service and those of contemporary end-of-life care for facilitating deaths at home. Whilst all the staff were cognisant of the current emphasis on dying at home and thought it a credible aim, it contradicted their alternative professional focus on treating seriously unwell patients through an urgent transfer to hospital. Navigating this difference seemed to be difficult, not just for the interviewees, but also for their superiors, and was exacerbated by issues of autonomy outlined previously. In the next section I explore a third problem for staff in keeping patients at home: the environment staff worked in.
3 The ambulance environment

Ambulance crew were working in situations which hindered their ability to keep a patient at home. It was typical for interviewees to only have the most basic information about the case-patient's history or their end-of-life preferences. The majority of the case-patient admissions occurred ‘out-of-hours’ when support from other healthcare services was limited. Both of these obstructed the ability of ambulance staff to organise care necessary for dying patients to be left at home. Interviewees described only being called to case-patients when community staff or family carers felt they had exhausted all other known community resources, which in turn reduced the ability of staff to keep patients at home. In the next section, I explore each of these dilemmas in turn.

3.1 Patient information

Ambulance staff often lacked patient information to aid decision-making. Patient preferences were recognised to be a powerful justification for keeping a patient at home, whilst not knowing whether a patient was ‘end-of-life’ emphasised concerns about negligence.

To understand what had happened to the patient prior to their involvement, ambulance staff were reliant on those who were present with the patient and their own clinical judgement. None of the ambulance interviewees described retrieving information from patient records, and it was unlikely that they would have had access to them [335]. The case-patients themselves were often too ill to be able to communicate effectively. Family carers were thus key but less than comprehensive sources, as AS Lunn described:

“SH: We’ve talked about his preferences about going into hospital, do you know if there were any family preferences or indeed [Mr French]’s own preferences about where he wanted to die and whether yeah just really where he wanted to die?

NL: I think on… we didn’t have any information given directly to us and I think we asked initially if he had any kind of care plan or was he on any kind of Liverpool Care Pathway, anything like that, and the response from the family was such that it didn’t mean anything much to them so we took that to mean that there wasn’t anything in terms of, in place that had been arranged with the family with [Mr French] and with their GP with relation to the kind of end-of-life care, yeah, the questions that we’d asked them we kind of got responses from that would indicate that it was something that had been discussed, but they weren’t forthcoming really.

[...Discussion about keeping a patient at home]
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SH: Yes, that’s a very hard thing to do knowing that you’re leaving, if you leave them that’s...

NL: I think, yeah, in the absence of all that and in the absence of any direction from the family you’re back to doing what clinically you know will give that person the best outcome, when there’s input from the family in terms of what they would like to do or of course the patient themselves, then that carries a huge weight as well.”(19,5)

Whilst ‘arriving as strangers’ [328] is a typical experience for ambulance staff, for the case-patients, it often meant that transfer to hospital became an inevitability. Seeking support from the family is accepted ambulance practice, but is limited to what family know and can articulate [339], and an absence of recorded patient wishes is routinely reported [324]. Without this or documented decision-making about the end-of-life meant AS Lunn felt obliged to revert to clinical best practice –”you’re back to doing what clinically you know will give that person the best outcome”(19,5) – and in doing so negated any community planning that may have occurred to keep Mr French at home.

3.2 Reversible illness

Missing information also had clinical consequences, because it meant that if staff were assessing hospital care based on the likelihood of the patient recovering, they were primarily reliant on the patient’s present condition, which is often difficult [336]. This was the situation for AS Burks:

“SH: Patients who die I suppose shortly after admission, so within a few days, I wondered what you thought about, admissions where patients die within a few days are seen as almost undesirable in some way, the kind of end-of-life issue and I wondered how you thought about that?

RB: Well it’s obviously, it’s not a good feeling if it is clear that you’re taking someone to hospital who’s, you know, who doesn’t stand a very good chance of leaving there, you know of coming out again. You know, it well, it’s a bit hard really I guess isn’t it because you never know someone’s outcome. It’s very tough to say really because on one hand you kind of feel you have to give someone every chance but then you come to a point where it may not be appropriate.”(29,4)

Being able to accurately prognosticate was a critical problem because knowing if Mrs O’Sullivan was likely to die imminently helped AS Burks judge whether hospital or home would be an appropriate destination. However, this decision is recognised to be difficult to establish for ambulance staff, in part because they only have limited medical technology to facilitate decision-making [340].
4 Community provision

4.1 Working out-of-hours

Much of the care ambulance staff were providing to case-patients occurred out-of-hours, when support from other community based services is limited. The community provision used by end-of-life patients, such as general practice, district nursing and associated services are only available at full capacity during office hours. This became a difficulty for ambulance staff when they wanted a second opinion. For example, the timing of Mrs Tonelli’s request to the ambulance service meant that staff could not easily reach her GP to arrange additional community support, as AS Simons stated:

“SH: You said about you, your initial kind of reaction would have been to leave her at home. And get them there as quickly as possible.

GS: Yeah, yeah, I mean by far it wasn’t ideal but I remember us both saying after the job that it really isn’t ideal but you look at it and you say “Well what else could you have done really?” We wouldn’t have got the doctor out, if it had happened two hours later in the day we could have phoned her GP and the GP I’m sure would have come straight out or someone would have come straight out, something could have been put in place but with how poor the out-of-hours service is, it’s impossible to set up something like that that’s got absolutely nothing to go on either and the doctor that’s never met her before. It’s difficult.”(23,3)

AS Simons had been called out to Mrs Tonelli at 7am, two-hours before the start of the ‘working-day’, which significantly restricted the care he could quickly arrange for her. A particular challenge found by ambulance interviewees was in accessing out-of-hours GP support, which was accessed through the 111 telephone service. The service had at the time only recently been introduced to the county, and the current protocol, as AS Simons remarked, was frustrating for staff seeking urgent advice: “The number that we go through, it’s the exact same number as ‘Joe Bloggs’ and the public goes through so we sit in the same queue as them, we wait for a call back in the same queue as everyone else”(23,5). For a GP to then visit a patient meant a further wait, which as earlier described was often considered too long (section 2.1.2). Without quick access to the GP, and concerned about the capability of the care home staff to look after her, hospital offered a viable alternative to AS Simons to unsatisfactory home provision. As found in the previous chapter, hospital meant accessible care and importantly, a medical authority to whom AS Simons could pass on the responsibility of Mrs Tonelli’s care.
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4.2 Arranging alternative care

If staff decided to leave a patient at home rather than take them to the hospital, it was expected that they would arrange onward care, as AS Darby explained:

“SH: And you just have to walk away?

KD: Leave them. You would obviously set up a pathway so obviously you would try and get GPs to come in. You would speak to district nurses. If they had cancer you would try and get, you know, some sort of cancer nursing, you know, or speak to the GP about getting a, like one of these little emergency packs. I think they’re called Just In Case packs or something like that, and you’d get all that in place so that when it did happen they would be comfortable and the family could be supported. But other than that you’ve got to bide by their wishes.”(18,9-10)

The need to “set up a pathway”(18,9) was expressed by several ambulance staff and reflects ambulance policy, but was made difficult by their limited access to other healthcare providers, in turn exacerbated if staff were working out of hours [323]. Whilst available evidence of end-of-life planning facilitated leaving a patient at home, as AS Darby noted in the earlier quote, the absence of it made keeping a patient at home more difficult. Like the hospital staff outlined in the previous chapter, ambulance staff were at a disadvantage for setting-up care because they were less likely to have established relationships with staff to be able to negotiate access. AS Darby for instance found that with patients “at the end of their last legs, but because it’s not been cancer they won’t all come out. The GP will come out but you can’t get anybody else out”(18,6). In these situations, staff felt they had little option but to take patients to hospital.

4.3 Community back up

Ambulance crew were often called to patients in situations when there was a perceived emergency; as AS Darby stated “I mean the fact that they called us and we didn’t just come across that address by accident, we went there because they called us for help”(18,4). This variously was because a patient was experiencing an acute exacerbation (Mr French), where home was no longer a conducive care environment (Mrs Thompson), where community care provision had been exhausted (Mrs O’Sullivan) or simply where it was known that a patient was dying and care home staff could no longer support her (Mrs Tonelli). It was unsurprising therefore that staff felt limited in the care they could provide for the patient at home. For instance, taking Mrs Tonelli to hospital was thought to be the only option(22,3) by AS Mitchell:

“SH: And you knew she was... You were taking her to somewhere that she was gonna be cared for, so...
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TM: Yes, yeah. Yeah, I mean, I don’t, I’m not sure. I was speaking to the doctor afterwards, and there was not much that they could do for her anyway. But they were just gonna do, go through the motions as such just to do their best, but it was pretty much looking at her body it was a lost cause. However, yeah, it’s somewhere to take her rather than go there... I had no other options really, it was the only option, to take her to here to let them carry on the care.”(22,2-3)

AS Mitchell’s decision to take Mrs Tonelli to hospital, even though she “was a lost cause”(22,2) emphasises again the conception of hospital as a place of safety. The limited choices of the ambulance staff in this situation was also acknowledged by some hospital interviewees. The decision of AS Watts’ to bring Mrs Thompson to hospital, for instance, was viewed by A&E doctor Dr Price as follows:

“HP: but actually, you know, I think they [Mrs Thompson’s family] called for help because help was needed, and the paramedics came the only place that they had access to, and actually the only place that has access to the only treatment that’s going to help.”(13,7)

In practice then, the need for ambulance staff to take case-patients to hospital was not only because they had limited autonomy, or the persistence of the idea of the ambulance service as a transfer medium, or the environment that staff were working in, but because hospital was the only accessible place that offered emergency care, and, if necessary, treatment. In this context, discussions about the relative appropriateness of hospital admissions seem irrelevant, because it was the “only place”(13,7).

5 Calling for help

The reason the ambulance service were so critical in these admissions is that they were called when other services were unavailable, and when patients were in need. Before concluding, it is necessary to explore one other service which could have provided similar help but whose role was noticeably missing in the admission of the case-patients: the GP out-of-hours service.

5.1 Out of hours

The absence of family or patient-initiated support from the GP out-of-hours service is apparent from the above discussion. Of the six case-patients admitted ‘out of hours’, the GP out-of-hours service was involved in only two cases and in none did they facilitate the admission to hospital. Following her collapse, carers for Mrs Hardwick telephoned the service, but before the service contacted her again a second telephone call had been made by someone at home to the ambulance service who then took her to hospital. Care home
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staff had initially contacted 111, for Mrs Tonelli but the call was then triaged to the ambulance service.

The limited role of the GP out-of-hours service may be explained by being relatively unknown and indirect, as ward doctor Dr Patel, outlined:

“SH: How unusual is incidences like [Mrs Brett]’s where someone comes in and they need, where a) a diagnosis has only recently been happened and that there is such a clinical need for them to be in and it’s a...

AP: As a [doctor] I probably see, I’ve seen quite a lot of cases, so it’s not unusual because it happens and to be honest, sometimes it’s just ‘cos they can’t get hold of anyone out of hours or they’re not sure whom to contact, so they just bring them in and even from a nursing home point of view, you know, rather than contacting a GP, the out of hours GP or whoever, they will just bring them into hospital straightaway.”(2,8)

The difficulties of contacting the service have been outlined previously (section 4.1), and are likely to have put off patients who felt that their symptoms were urgent. Not being able to access the hospital “straightaway”(2,8) accorded with Mr Clarkson’s experience. When Mrs Clarkson experienced chest pain her son Mr Clarkson had decided to take her to hospital himself. When her symptoms worsened, he decided instead to call for an ambulance. From previous experience, the GP out-of-hours service would be “unhelpful”(9,4) according to Mr Clarkson:

“SH: And was the GP involved at all?

DC: No. It was a Saturday so our GP surgery is closed on a Saturday so it would have been a locum doctor, an out-of-hours and on previous occasions it wasn’t worth trying to phone them so.

SH: Because it takes so long?

DC: It takes so long and they’re unhelpful, they don’t know the case so much better to send her somewhere where people know what’s going on, they’ve got all the paperwork, plus the fact that the chest pains, in case it was something serious, it’s not something. I don’t need the doctor to tell me that the chest pains are serious so.”(9,4)

Unlike Mrs Clarkson’s usual GP or the hospital, the GP out-of-hours service according to Mr Clarkson would not know his mum and her condition, and without “the paperwork”(9,4) of her medical records was presumed to be of little help. Moreover, Mr Clarkson did not value their advice. The hospital, being “somewhere where people know what’s going on”(9,4) was more authoritative than the out-of-hours service, and since he felt his Mum’s condition was particularly serious, their involvement would only
unnecessarily delay things. This perception of the inability of out-of-hours staff to respond to critical care was also thought to apply to formal carers. Dr Sun, an A&E doctor, felt that if care home staff thought a patient’s condition was an emergency then the out-of-hours service would be bypassed for hospital care. Describing Mrs Williams’ admission to hospital, Dr Sun stated that “maybe they could have called the GP out-of-hours maybe, but they thought it was an emergency so they came in”(27,4). The GP out-of-hours service thus seemed hindered by its intermediary position in addressing the hospital admissions of the case-patients.

The view of out-of-hours GP provision as detached meant it provided neither the familiarity of the doctors’ surgery, nor had the immediacy or gravity presumed of the hospital service, and was therefore neglected as a source of care. Yet even where these features were not applicable, the out-of-hours service was not used. For Mr Saunders, GP out-of-hours help came from his own GP practice. The service was described as comprehensive and personal by his GP, Dr Chapman:

"GC: Yeah. I mean I don’t know, that’s a very personal thing but most people want to die at home right? Surrounded by, you know, their friends, family and everything else, and as we still offer twenty-four hour, seven days a week service for the dying home, just because [(mumbled)] live in the village and we can get there and it seems a bit churlish not to turn up if people are in extremis, I mean I'll visit people on Christmas day if needs be. And we’re also at the end of the phone, even if I'm doing shopping in [town] they can phone me, they've got my mobile phone and can use my mobile phone number, you know, that’s what people want and I think people should be, [supported to die at home]"(4,5)

Whilst Mr and Mrs Saunders knew about his personal availability at all times (Dr Chapman visited Mr Saunders the weekend before his death), they did not call him at the time of his admission. According to Mrs Saunders, Mr Saunders telephoned the ambulance service because he wanted to die in hospital, perhaps because he thought Dr Chapman would not admit him. Like Mr Clarkson organising Mrs Clarkson’s care, Mr Saunders knew he wanted hospital care, and the ambulance service was a quick way to facilitate this. The out-of-hours service by comparison for the case-patients care was conceived as slow, with limited authority and lacking patient information.

5.1.1 Seeking hospital care

This is consistent with the limited research conducted on why end-of-life care patients seek hospital care [341]. Whilst some sought the ambulance service because they did not know who else to contact when a patient needed urgent care [342], prior experience of
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the out-of-hours service was important. If previously patients had been told to go to hospital after being assessed by the out-of-hours service, or if they felt that patients had a condition that could only be treated in hospital (as with Mrs Clarkson’s chest pains) then the out-of-hours service became an inefficient intermediary [343]. By comparison, the ambulance service was recognised as a quick conduit to hospital when patients had symptoms which they or their family believed needed care there [344]. Moreover, this hesitance to use out-of-hours services may also reflect awareness of the service as Dr Patel suggested; the Ipsos MORI [345] July GP survey found that nearly half of all patients did not know how to contact their OOH GP service.

6 Conclusion

Ambulance staff occupied a critical role between home and hospital for case-patients, but were restricted in what they could do to prevent admissions. It is difficult to see how hospital for the case-patients could have been avoided. Patients were conveyed to hospital, sometimes reluctantly, because it offered accessible care and the best setting potentially to reverse their condition. Whilst it was recognised that there had been attempts at a policy level to divert staff from considering hospital as a default setting for end-of-life patients, the structural issues that the ambulance interviewees experienced meant that the hospital was conceived as the only option. Providing care to dying patients meant navigating contradictory aims of the service, end-of-life care and their own beliefs about what appropriate care looked like. Staff were highly skilled and knowledgeable about end-of-life care, but did not feel legitimated to make the decision to keep a dying patient at home on their own because it was thought to counter the informal aims of the service.

Whilst for analytic reasons I have presented each of these issues as a distinct problem, in practice it was their combined effect which seemed to constrain the ability of ambulance staff to keep patients at home. The problems they faced were also experienced to a lesser degree by other healthcare staff, and demonstrate the challenges in providing end-of-life care.

The chapter raised a number of sociological ideas which I address in the following chapter. To understand more about how the hospital was conceived as a default choice it is useful to consider the work of Bittner [346] on the police as an extensive emergency resource beyond the accepted scope of law enforcement. The inability of the ambulance staff to overcome the constraints they experienced raises questions of authority and
professional status, which I explore by looking at the work of Etzioni [192] on ‘semi-professions’ and Johnson [347] on forms of professionalism. Etzioni [192] also helps explain the different emphases by healthcare staff towards end-of-life care planning for directing behaviour.
Chapter eight

“\text{It is not easy at a patient’s home to explain on the telephone to junior doctors that one is well aware that there are scant clinical grounds for admission but that the home situation and patient’s carer’s expectations are such that there is no feasible alternative. In such circumstances admission is appropriate.}”

[187]
Chapter 8

A sociological perspective on end-of-life admissions

It is apparent from the previous chapters that end-of-life admissions cannot be satisfactorily understood within the dichotomies inherent in the pejorative binary labelling of them, as ‘appropriate’ or ‘inappropriate’. The accounts about the case-patients’ admissions, together with the factors identified as contributing to their policy formation as problematic, demonstrate that the reasons for admissions are multi-faceted and inherently social, reflecting the demands and pressures on those involved.

In this chapter I consider some of these reasons for admission, pulling together themes from previous chapters with reference to classic sociological literature on organisations, language, bureaucracy, the professions and typifications in order to reach a social understanding of hospital admissions. The approach has been to explore the classic texts where ideas which are now commonplace and taken for granted, such as bureaucracy and profession, originate, in order to illuminate the processes observed in the accounts of the interviewees. This classic literature remains a source of insight, and in turn informed the overarching theoretical approach in this thesis of the interplay of structure and agency developed by Giddens. I complement this analysis with a contemporary working of social practice theory, which itself draws on structuration theory to illuminate how and why the practice of end-of-life admissions occurs and thrives.

First, I address the questions identified in the previous four chapters. Reflecting the diversity of problems, the theories I draw upon to answer them are similarly varied. Common to each however is a clear understanding of social life, and it is this that makes them transferable to the often comparatively foreign topic of end-of-life admissions (188)p.xxii).

Second, I draw these answers together using Shove et al.’s [348] interpretation of social practice theory to understand the practice of ‘end-of-life admissions’. I begin this section by exploring the component practices of home and hospital care to understand how home could become a problematic place of care, and how hospital could be both derided and
sought after. I conclude by considering the impact of the emphasis of planning on how admissions were constructed in the discourse of admissions by interviewees.

Throughout I stress how the actions of healthcare staff, patients and their family reflected the social system in which they were operating in, constraining and enabling their actions. The hospital, amidst this, was concurrently just another essential resource in the care of the case-patients, and a place tightly bound with negative associations, and this dual status added significantly to the everyday challenge of providing end-of-life care.

1 Empirical problems
1.1 Planning for end-of-life care

End-of-life care policy emphasises the need to organise and plan for dying. In practice, the care case-patients received often did not meet the neat ideal modelled in policy documentation, and their admission was attributed to the absence of planning by some interviewees (chapter 6). Exploring why care did not follow that modelled in policy is essential for understanding the case-patients’ hospital admissions. I do so by using Burns’ and Stalkers’ [191] model of mechanical and organic organisation, starting by considering how care was designed to be delivered, exploring ideas of bureaucracy. I address next the problems encountered by staff which hindered their efforts to follow this model, and consider how in practice care occurred. In doing so, I recast the ‘problems’ encountered by staff as inherent factors in the case-patients’ care. I argue that the messy, ‘unplanned’ organisation which occurred for many of the case-patients was a practical and pragmatic approach to addressing the apparent uncertainty in end-of-life care.

1.1.1 Mechanical model care

Planning is a central component in English end-of-life care policy, which supposedly provides a neat, sequential process for organising end-of-life care. The end-of-life care pathway in the EOLCS constructs dying as a unidirectional process (chapter 3). Planning is considered a solution to “poorly coordinated services and inefficient processes”([1]p.55), with the EOLCS designed to improve the quality and efficiency of the organisation of care through documented decision-making, written protocols, and established care pathways. Whilst the Pathway is only a model of the EOLCS it encapsulates the rhetoric that dying can be planned and organised for, which has persisted in subsequent updated models of end-of-life care (chapter 3).
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The idea that end-of-life care can be planned and organised for was explicit in the language used by staff and negatively coloured their view of the case-patients admission which were often presumed to be a failure of planning, whereby their language is indicative of the culture of end-of-life care (chapter 6, sections 3.1, 3.2.2; cf [349]). Furthermore, even staff critical of the current measures for organising end-of-life care, still discussed admissions in normative terms which implied that admissions could be controlled through planning. This appears related to the prevalent descriptions of admissions, where terms like ‘preventable’ and ‘avoidable’ promote the idea that if an admission is not pre-planned it must by consequence be ‘inappropriate’, such that their conclusions were shaped by the language they used to describe admissions [189].

The planned approach to organising end-of-life care has many commonalities with Burns and Stalker’s [191] idea of mechanical organisation, developed in the contexts of the electronics industry in Britain in the late 1950s. This is supposedly a highly efficient and rational way of organising work, which operates well in a stable environment ([191]p.120). Organisation of care in this instance, is broken down into functional tasks (as with the Pathway, where end-of-life care is split into steps), with each individual task abstract, such that it requires a distinct technique with the task focus typically on improving the process, rather than contributing to the general whole (each Pathway step for instance is separate to the previous: step 2 about care-planning exclusively, step 3 about coordinating services, and so on) ([191]p.120). Supervisors ensure that these tasks join together, and there is a hierarchy of control, authority and communication, with a clear chain of command (here responsibility is typically given to the GP, who is expected to be knowledge about the patient and to facilitate care) ([191]p.120). Each role has clearly defined rights, obligations, methods and responsibilities, with formalised procedures strongly adhered to ([191]p.120). In its totality, mechanical organisation can be considered to be about the breaking down of a single undertaking (end-of-life care) into discrete tasks, which when pieced together (often sequentially), allow for the undertaking to be completed efficiently ([191]p.5).

The idea of mechanical organisation, although Durkheimian in origin, has much in common with bureaucratic principles, for which Weber’s [350] model provides a useful steer, and elucidates the importance of rules which are central for mechanical organisation to occur. Bureaucratic organisation also involves an emphasis on hierarchy, worker roles with explicit rights and responsibilities from their employer, and an emphasis on roles not being tied to an individual [350]. But it is the abstract, general
and clearly defined rules that are critical, since these prevent the need to give specific instructions for each case, and mean that individual problems are classified against set criteria and treated accordingly, as the classic commentary by Merton makes clear ([351]p.561). The principle of these rules allows for models like the Pathway to set standards in how individual care is organised and arranged, but becomes difficult when the rules –here the sequences of end-of-life care- do not fit the problems they are designed to address.

### 1.1.2 Problems in planning

Case-patients’ care often did not match the neat sequences suggested in the Pathway, with each case appearing to be disjointed and improvised. I argue next that this was not because staff purposefully deviated from the mechanical model proposed in policy, but because of the real-life problems encountered by interviewees.

Staff frequently had difficulties facilitating care for patients. They struggled to plan and facilitate care where a patient’s prognosis was uncertain, or where it deviated from the expected trajectory (see also section 2.4). Missing information exacerbated this problem, making it difficult to know what care had been arranged for the patient, and which only sometimes could be supplanted by material from others. The absence of accessible community care also challenged staff ability to provide the care they wished to arrange for patients.

Following plans moreover was not necessarily straightforward, especially where it involved collaboration with others or where it was a new professional partnership. This was in part because it was often not clear what the ‘right’ thing to do was. This was particularly pertinent when staff discussed the decision about whether to facilitate a case-patients’ admission to hospital. Here they had to navigate contradictory policies regarding the best care for patients between: their occupation and end-of-life care best practices; their occupation and their individual beliefs; and what was appropriate clinically to do for the patient and the wishes or needs of the family (chapter 6, 7).

In these situations, staff necessarily had to deviate from the mechanical approach of expected protocol in order to provide care for dying patients. Instead, they adopted a more flexible approach to organising care.
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1.1.3 Organic organisation

Organic organisation is the polar opposite to mechanical organisation ([191]p.122). Neither approach is ‘better’, but organic organisation is more suited to unstable or unpredictable situations. It works where problems cannot be broken down into discrete tasks, such as where staff did not know about prior arrangements for patients, or how long a patient would live or where community care provision was uncertain ([191]p.5-6).

To be effective in changing situations, organic organisation requires multiple associations between groups and horizontal as well as vertical communication, such that it is less about command and more about consultation. Tasks are not neatly defined, but are related to the final product and are readjusted as necessary to fit the current situation as decided through interaction with others (seen for instance in the collaboration between the specialist nurse and GP, or between the hospital and GP (chapter 6)). Organic organisation is a model that demands cooperation and requires responsibility to be accepted by all participants, and for it to extend to the final product, rather than only to their set task ([191]p.125). In-person communication is typically prioritised over a written form in order to accommodate change, and there is less emphasis on process ([191]p.92). Groups communicate for information and advice, rather than for instructions or decisions. Control, knowledge and authority tend to be located throughout the network rather than necessarily with the most senior, and conduct is governed by presumed mutual interest for the overall aim ([191]p.121).

Whilst it is apparent that some aspects of end-of-life care planning was mechanical, seen for instance in the successful promotion of documented resuscitation orders, primarily staff described an approach which tended more towards organic organisation. Paradoxically, this was demonstrated in the continual emphasis by staff on greater end-of-life planning, which suggests both the importance of language, which hindered staff ability to consider admissions alternatively, and that care was not routinely organised in this way ([191]p.123). Such calls demonstrate too that the organic approach was not purposefully chosen, but rather reflected the scenarios staff were providing care in. A significant problem seemed to be the number of groups of healthcare staff involved, which hindered continuous care and the straightforward transfer of patient responsibility between staff. I explore next the consequences of this diversity.
1.1.4 Group differences

Group diversity is significant for the way in which care was organised, because any form of mechanical organisation requires similarity between those involved ([352] p.101). The groups differed however even in how they dressed and spoke. Staff wore different prescribed work uniforms, indicative of discrete group identities ([353]p.127), ([352]p.262). Speech patterns were also distinctive. Ambulance staff speech for instance was noticeable for being well dispersed with acronyms and specialist language, telling of a close-knit community where shared language meant that abbreviations could be effectively used [190] . These apparently superficial differences can point to more significant differences in approaches to planning. Thus in the electronics factories studied by Burns and Stalker [191] the ‘long-haired’ researchers were distinctive to the more conservatively dressed factory workers, with significant variance in the way they organised themselves professionally.

Such differences can also be drawn between how the groups involved in the case-patients care organised themselves. It can be expected that healthcare ‘professionals’ (exclusively doctor interviewees in this context), will organise themselves differently to, to use Etzioni’s term ‘semi-professionals’ (ambulance staff, nurses, a point I justify in section 1.2) [192]. This is because in medical practices there is a clearer distinction between administrative and ‘professional’ (clinical) roles than in ‘semi-professional’ places of work.

Administrative roles are likely to be organised bureaucratically, whilst knowledge-based roles, such as doctors, use professional authority which can only be awkwardly coordinated in this way([192] p.76); Etzioni was one of the first to elucidate these differences, and his account remains relevant today. Bureaucracies depend on a clear distinction between the individual and the office they hold, with no role ‘owned’ by an individual, whilst professional authority is tied to the individual. Professional knowledge by contrast cannot be directly passed from one person to another and is highly regarded, seen for instance in justifications for professional actions, which are given on the recommendation that it is the right thing to do, according to their professional knowledge ([192]p.77). Solely professional organisations therefore typically have much flatter organisational structures which can encompass this authority. Organisations like GP practices and hospitals which need to include both forms of roles therefore include both types of organisation, which are clearly delineated. Ambulance staff by contrast are
likely to work in a service which does not have such a distinction between administrative and professional authority.

These differences have practical consequences. Those working in organisations which are solely professional, or where there is a clear delineation between roles, for instance are likely to be more resistant to administrative processes. Those working in organisations that combine administrative and professional roles are more likely to accept administratively organised work, whether through choice or because they can less easily resist bureaucratic influences ([192]; [354]p.236). The consequences of this is seen in different priorities between staff groups about recorded end-of-life care planning. Ambulance staff strongly emphasised the importance of it, whilst GP interviewees described a less formal approach to it which did not always culminate in recorded end-of-life care plans.

These differences demonstrate that it cannot be presumed that healthcare groups will organise or think about end-of-life care in the same way, or be able to effectively collaborate. Whilst the consequences of group (or individual) differences could be negligible where care followed expected pathways, in situations where care was less straightforward to organise, such as when it was necessary to organise care at late notice, these differences could be so significant as to discourage coordination, as occurred with ambulance staff arranging home care. In this context, it often became necessary to modify the sequential, mechanical approach ascribed by policy, in order to facilitate care.

Mechanical organisation is not an inherently a poor idea, despite the negative connotations of bureaucracy ([355]p.159-160). It is essential for instance on a broad level for the NHS, which as a body organising care for the nation on behalf of the state, necessarily requires standardisation and efficiency in order to cope with the needs of the service and the scale of patients cared for ([347] p.85). Even within end-of-life care, the products of mechanical organisation are broadly useful and necessary: documentation like Do Not Attempt Cardio-Pulmonary Resuscitation for example prevents patients being continually asked about their treatment preferences. However, it became problematic where it was too prescriptive, and when the care modelled did not match the needs of the patients or staff: points I explore further below (section 2.4).\textsuperscript{57}

1.2 The limited authority of ambulance staff

Ambulance staff were key arbiters in the decision to admit patients to hospital, but were limited in their ability to keep patients at home because of the environment they were
working in, particularly because they lacked authority to keep patients at home (chapter 7). To explore why this was so, I consider the idea of professionalism, drawing particularly on Etzioni’s [192] idea of a ‘semi-profession’, as well as considering briefly the political attempts to change the professional status of the ambulance service.

1.2.1 Professionalism

Ambulance staff did not take case-patients to hospital because they wished to be absolved of their own obligation to the patients, but because it was beyond their recognised authority to do anything other than admit the case-patients. It suggests that ambulance staff can be considered ‘semi-professional’ within traditional work structures [192]. Unlike their doctor peers, ambulance staff had far less autonomy, were under greater management control and had less scope for individual discretion to do non-prescribed work or to exercise professional judgement ([192] p.87-8). They also had restricted opportunity to apply knowledge or to have significant responsibility for life or death decision-making in performing their duties, demonstrated by the limited scope to deviate from protocol and keep patients at home ([192]p.88). Unlike the work of doctors in the study, ambulance work was highly regulated, both in terms of the working day and the activities that they performed within it, meaning that any deviations are likely to have been known and challenged by management ([192]p.88). Whilst staff were working beyond the direct control of their superiors their conduct was reviewed remotely ([192]p.88), such that their adherence to rules was important (cf [354]). This was evident in their emphasis on documented decision-making, as well as close recording of their own behaviour (chapter 7, section 1).

1.2.2 Policy

The ambulance service has however been through a period of transition in recent decades, with diligent attempts to ‘professionalise’ [326]. The New Labour government sought to restructure the ambulance service, together with other ‘non-professional’ organisations within the NHS as Allied Health Professionals. The ambulance service professionalism focused on paramedics, who were distinguished from other ambulance staff. Paramedics joined what is now the Health and Care Professions Council in 2000, the term paramedic became a protected title, and a professional association was established [361]. Training is moving to being exclusively provided in a higher education setting and there is an explicit code of conduct and ethics [361]. Together, this fulfils may of the attributes recognised of a profession [362].
However, despite the appropriate apparatus, the ambulance service bears many of the hallmarks of a ‘semi-profession’, with little recognition of the status of the service, or evidence of a discrete body of knowledge expected of a ‘professional’ organisation ([347]pp.56-57). As outlined in chapter 7, the status of the ambulance service is uncertain (section 2.2.1), reflecting in part the difficulties of emergency medicine, which only recently (2008) gained symbolic acceptance as a medical speciality when a Royal College was established for it [363]. This in turn further challenged the idea of a distinct knowledge domain for the ambulance service, which had already been encroached by voluntary first-aid organisations.

The lack of ‘professional’ status of the ambulance service is in many ways unsurprising given that the conditions which allowed for the growth of professions in the nineteenth century in Britain have largely disappeared. The Industrial Revolution led to a burgeoning middle class who sought the services of doctors, lawyers and architects and others. The increasing demand led what had been small ‘cliques’ serving the elite to became large associations with parity of (powerful) social status to their clients, from which the establishment of professional associations derived as a means of occupational control over the producer-consumer relationship ([347] p.45, 52-53). By contrast, the ambulance service, can be considered within a form of mediative occupational control, whereby the state acts both as an employer and supplier of patients, in line with other healthcare staff [347]. This form of control in turn inhibits the development of the occupation as a profession, despite government attempts otherwise. The involvement of the state moderates the power of professional associations and means it is more difficult to dictate practice, whilst encouraging fragmentation thereby hindering the cohesion necessary for a successful professional organisation ([347] p.80).

Furthermore, whilst the process of professionalism was purported to give more professional discretion to paramedics, the concurrent setting of performance targets and audit measures by the government in practice extended government control over the ‘professions’ [326]. The limited ability of staff to exercise their autonomy therefore suggests that the service could still be usefully considered a ‘semi-profession’, helping to explain the challenge staff had in keeping end-of-life patients at home.

### 1.3 End-of-life hospital patients: Unwelcome, but accepted

The case-patients care needs were not thought to be best met in the hospital and accordingly their admission caused difficulties for hospital staff. In this section I explore
why this was so by considering Etzioni’s [192] elaboration of institutional goals as applied to Meadowbridge. I consider the consequences of this for staff in the care they provided to case-patients by referring to ideas derived from Strong [280] and May and Kelly [279]. Through this, I argue that the case-patients were an awkward fit within the current environment because of the persistent hospital emphasis on acute care.

1.3.1 Not a priority

Case-patients were considered to have fitted poorly within Meadowbridge by interviewees because they did not have an acute illness, thereby contravening the role, or goal, of the hospital (chapter 5, section 2.1). Whilst Meadowbridge is likely to have pursued many goals concurrently as a large hospital, it seems plausible that care of the dying was not recognised to be a primary one. In line with all social organisations – that is any organisation of people, such as hospitals, armies, schools, corporations – goals structure the hospital and orientate work ([192]p.3). Importantly, the goals are used to legitimate organisational activities and serve to assess the effectiveness and the efficiency of the organisation([192]p.3). By not recognising the care provided to dying case-patients as contributing to a significant goal of the hospital, staff therefore struggled to legitimate the care they provided (chapter 5).

Such problems are unlikely to be held exclusively by staff interviewed. The negative portrayal of hospital as a site of death recognised in policy for instance, is justified in part because of the hospital focus on acute and curative care which does not match the aims of contemporary end-of-life expectations, thereby implying that care of the dying does not fit within current hospital care (see for instance chapter 3, section 2.2.1). More broadly, care of the elderly is recognised to be a poor fit to the hospital environment, despite representing an increasing task of the hospital [364].

There is also evidence that palliative care within the hospital is not wholly assimilated within the hospital setting. Whilst specialist palliative care teams are routinely located in hospitals, palliative care professionals acknowledge there can be problems associated with achieving legitimacy from hospital colleagues [365, 366]. The specialist palliative care team within Meadowbridge was recognised by interviewees with reference to both the service as a whole and to named consultants. It does not necessarily follow though that palliative care as a discipline was recognised as work of Meadowbridge, particularly for non-cancer patients, reflecting the historic emphasis on cancer care (chapter 3, section 1.4.2). Furthermore, the establishment of the discipline as a hospital speciality
may have challenged the propensity of non-specialist staff from recognising dying care as within their role, as demonstrated by comments about the suitability of care available within the hospital for dying patients (chapter 5, section 2, [270, 366]).

### 1.3.2 Staff perceptions of patients

The case-patients often seemed to frustrate hospital staff, and in this section I explore why. I argue that they felt this way because the patients were difficult to care for in the acute setting, did not legitimatise their role, and challenged the order of the hospital.

Whilst interviewees were clear that the dying experience was important and should be prioritised, they often outlined how they were unable to provide this care well. This seems likely to be attributed at least in part to the fact that the hospital could offer little material benefit to patients, echoing the conclusions of Strong [280]. His work considered the care of alcoholic patients by GPs, who were difficult to care for because of the limited effective care available, of which non-medical care dominated. Similarly, the case-patients were not recognised to be able to be ‘treated’ in Meadowbridge, therefore making their presence in hospital problematic, as outlined below (section 1.3). Worse, the limited treatment that hospital was recognised to be able to provide was primarily nursing care, which neither utilised the acute service of the hospital that staff were keen to stress, nor was thought to be of great benefit to patients because of the environment it was provided in. The organisation of the hospital in general was thought to be counter to good practice for dying patients, whereby care is organised by specialism requiring often multiple moves for the patient within the hospital, which were considered poor practice by interviewees (chapter 5, section 2.3; [364]). However, as with Strong [280]’s alcoholic patients, staff recognised a responsibility towards the case-patients, which meant that the patients could not be refused care (chapter 5, section 4.1). This need, juxtaposed with an apparently harmful therapeutic environment and the limited scope to provide appropriate ‘medical’ acute care means it is unsurprising that the case-patients occupied a difficult position for the interviewees.

Furthermore, it was also expected that these patients would require special care. Staff described in interviews trying to moderate the busy hospital environment which was deemed unsuitable for a ‘good death’, by putting patients in side rooms or not moving them to a ward in order to encourage continuity of care. Such tasks meant additional work for interviewees, and had consequences for the smooth organisation of the hospital [279]. In contravening usual practice, caring for case-patients in this way had the
potential to spoil the order and efficiency necessary for the smooth turnover of patients, particularly so within the A&E department which has high patient volume and a need to process patients quickly [263].

However, this additional care did not legitimise their role as a healthcare professional, because it was neither recognised as a goal of the hospital (section 1.3.1), and nor was it particularly medically orientated [367]. Thus it is unsurprising that these patients were not always positively described by healthcare staff. However, the acknowledgement that some patients were less legitimate than others seemed to cause considerable distress to staff, as demonstrated in the conflicted accounts hospital staff in particular gave about admissions (chapter 5, section 2.2, 6.1). This in turn is explained by reference to the role of the doctor, whereby affective neutrality is an important principle, such that feelings of frustration or dislike towards these patients challenge what it is to be a doctor [368].

1.4 Family coping

Many of the case-patients were cared for day-to-day by family members at home. This role was important and often demanding, as family carers absorbed much of the instability and uncertainty involved in the dying process, helping to reduce the likelihood of admissions (chapter 6). In the next section I consider how family members dealt with this role by building on Shutz’s [320] concept of typifications and the ‘stocks of knowledge’ they require. I argue that case-patients’ admissions occurred when the caring role breached the next-of-kin’s concept of ‘normal’ such that they no longer knew how to resolve the problems faced by the patient and therefore sought help.

Family carers who were not professionally trained, will have relied on knowledge they had acquired in their life previously to care for their relative. Their ‘stock of knowledge’ [320, 369] on caring is likely to have been derived from previous caring experiences such as looking after children, knowledge acquired from others, including information provided by healthcare providers and voluntary groups, as well as information gathered from everyday life, such as depictions of care in the media. Collectively, this ‘stock’ acts as a frame of reference for addressing problems and mediating what they were experiencing and how they thought about it; in short, typifications about what was ‘normal’ and what was not. By providing generalised notions of how things should be such the unfamiliar can become familiar, the stock of knowledge also plays a considerable role in providing ontological security, thereby facilitating our ability to ‘go on’ in everyday life [188]p.xxiii).
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The stock of knowledge is not static and can be added and amended too. As family carers understood more about their relatives’ illness and developed experiential knowledge of how to care for them, they may have become ‘expert’ [370]. Providing the stock is sufficient, it means that caring for a dying patient can become familiar and included within the routine of everyday life, even when facing the impending death of a loved one [371]. (In turn, the ‘everyday’ nature of dying also helps to explain why typical health-seeking behaviour – of seeking hospital care when the patient was ‘poorly’ – persisted even when a patient was dying (chapter 5, section 5.5)).

However, the knowledge held by carers may not necessarily be accurate, if for instance their knowledge of dying is based on idealised portrayals of death in the media (chapter 5, section 2.2.2). Where the typifications held by family carers was outside what they knew to expect from a particular illness, they are likely to have sought professional medical help [370]. This occurs when carers appraise a situation to be stressful and evaluate that with the resources available they cannot resolve the problem on their own [372]. A familiar change in symptoms for instance may only be considered problematic by family carers if they occur in combination with new symptoms or where help to resolve the problem is known to be unavailable quickly. Similarly, the apparent worsening of a condition may make a hospital admission more likely where family carers are unable to resolve the problem using existing techniques.

Considering coping in this way underlines the reflexive nature of caring for a dying patient, in that patient problems will not be considered in the same way by family carers all the time. This explains how family carers could absorb much of the uncertainty in end-of-life care, until they were in a situation which exceeded their available resources, and they instead sought help from others.

1.5 Hospital: undesirable, but a default place of care

The importance of the provision available at Meadowbridge was acknowledged by all interviewees. Despite recognition that hospital was a poor place of death, it was used as a safety-net by community staff, was a default place of care for ambulance staff, and end-of-life patients were admitted (albeit sometimes with reservations) by hospital staff. Practical concerns partly explain this use of hospital: it was the only resource universally recognised by interviewees as available, accessible and with obtainable nursing care (chapters 5-7). The identified responsibility felt by hospital staff towards end-of-life patients explains more (chapter 5, section 4.1), but even this is not wholly
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satisfying because it not clear why staff felt responsible to some patients (like the case-patients), but not to others (such as those who attend A&E but are not admitted). It therefore remains unclear why hospital staff legitimised the use of hospital as a place of safety, despite their emphasis on acute care provision as the central goal of the hospital. Since this seems a pertinent topic for understanding the occurrence of admissions, I explore this next, drawing upon the notion of ‘citizen demand’ [346].

The case-patients’ admissions were justified by hospital staff for a variety of reasons including: nursing, diagnosis of symptoms, emergency medical attention and that a patient had called for help (chapter 5-7). Common to each of these reasons was an emphasis on patient need. This has parallels to the work of the police, for whom the concept of citizen demand unifies their otherwise disparate labour, which expands far beyond the common-sense remit of fighting crime, to encompass saving cats to addressing noise disturbance and traffic management [346]. For admission to hospital, the act of someone identifying that a patient had a problem was enough for their needs to be considered sufficiently within the remit of the hospital to warrant admission. This was recognised by community staff, such that case-patients were sent to Meadowbridge for non-acute care. Their admission was in turn accepted by hospital staff because the patients were recognised to have a need which the hospital could meet (cf [346]).

Given this useful role, it is surprising that the hospital is persistently negatively recognised in end-of-life care. Whilst there are many tangible factors that contribute toward this— the creation of palliative care, the current emphasis on place of death, desires to have fewer patients in hospital generally, for instance (chapter 3) – I have not addressed the mechanisms for its persistence, which is relevant for my understanding of hospital admissions as ‘inappropriate’. To do so, Giddens’ theory of structuration, first considered in chapter 4, is useful.

The hospital, is ‘deeply-sedimented’ as a social institution, in that it is a widely recognised place of medical care and has persisted over the last two centuries in a form similar to today (chapter 3, [373]p.80). The concept that dying should occur in the home rather than the hospital is similarly embedded within end-of-life care provision; whilst the normative emphasis on place and death is recent, the consequences of the practice is wide-ranging, extending beyond medical provision to how care is organised, death is perceived and seemingly affecting a diverse array of healthcare staff ([373]p.64-5). Understanding how this sedimented process occurs provides useful context for thinking about admissions.
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Practices that constitute the hospital as a place of care in medical need, and the promotion that home is a good place of death compared to a poor one in hospital, become sedimented through repeated use ([374]p.10). The more that we as members of society seek hospital care when we or others are ill, or conversely facilitate death at home such as through ideas advocated in the EOLCS, the more these practices are reinforced and become ‘fixed’ ([188]p.22). In turn these practices contribute to the conventions that we abide by in order to ‘go on’ with daily life ([188]p.64,[375]p.83), so that when we are caring for someone who is dying it is recognised that the ideal place of death is home. Whilst the concept of dying at home appears immutable, continued recursive practice is necessary for their continued existence as anything but memory traces ([188]p.17).

Understanding how practices are sedimented is fundamental for understanding admissions, helping to explain why hospital was both derided and sought after at the end-of-life. What remains unresolved is the impact these had on staff facilitating care, which I consider next, and how these contradictory, embedded practices interrelate which I explore later through the use of a social practice theory.

1.6 Deciding to facilitate admissions

Community staff, when faced with a patient who needed additional care that could not be provided easily within the home environment, articulated a dilemma between keeping a patient at home in discomfort, or facilitating their admission to the ‘undesirable’ hospital environment (chapter 6). This problem can usefully be considered within the terms of structure, as defined within structuration theory. I argue that admissions are at least in part due to the social environment of the individual, which affects their ability to provide care.

The transfer of end-of-life patients to hospital in order for them to receive care unavailable in the community could be considered a problem about ineffective or absent planning, as was sometimes presumed to be the reason by interviewees and intimated in policy (chapter 3, chapter 5). However, this situation can also be considered as a consequence of the effect of structure, as conceived above (section 1.5). The GPs for instance were often limited in keeping a case-patient at home because of the lack of easily available domiciliary nursing care. Access to resources, care in this instance, is a key way in which our actions are limited or enabled socially ([188]p.258-261). Deciding to facilitate an admission in order for a patient to receive care was however mediated by the GPs’ concern about the suitability of hospital as both a place of care, and a place of
death. The undesirability of hospital at the end-of-life can also be considered a product of structure, and was a significant factor in decision-making (section 1.5). Hospital appeared to be considered by staff to be an option only reluctantly, despite offering the care identified as necessary for the patients.

Structure also constrained staff decision-making. Community staff often struggled in deciding what was best to do for the patient in this situation, particularly where staff were inexperienced in addressing end-of-life issues. Their difficulty suggests that this was a problem that was not easily resolved by their ‘practical consciousness’ disrupting their ability to ‘go on’ in this situation in their role as healthcare staff, and challenging the routine of their practice ([188]p.xxiii, chapter 6, section 3.3.2). Both routines and practical consciousness are an expression of structure, given that they are at least in part impinged on by social rules (a form of structure (Giddens [188]p.19)), and as such the GPs actions also reinforced this structure.

This did not mean however that the GPs had no agency, nor that admission was a given outcome for the case-patients. Structure is a form of collective agency, in that it is formed by repeated social actions. Thus the collectively realised idea of the undesirability of hospital (and the desirability of home) occurs recursively from repeated individual actions (section 1.5). More directly, evidence of the GPs’ agency is found in their decision to send patients to hospital, despite its negative connotations. The social competence of the interviewees is demonstrated in their ability to both navigate this complicated arrangement and to articulate it.

It is evident that staff action was both enabled and constrained by the social environment they were working in, and creating. To explore more broadly the factors that lead both to admissions occurring, and how they came to be conceived as problematic, I turn next to social practices theory, which considers how social practices evolve, emerge and die ([348]p.4).

2 The practice of hospital admissions

2.1 A social practice theory

It is apparent that hospital admissions are an inherently social occurrence, reflecting structural pressures felt by staff, and, in their attempt to overcome or address these, the agency of individuals. To consider this further, I use social practice theory.
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Theories of social practice are plentiful ([19]p.6), and here I use the work of Shove et al. [348], whose application of social practice focuses on how practices reproduce and change, and does so by applying a straightforward concept of three elements, which I outline below (section 2.2). Their work is pertinent given that Giddens’ theory of structuration, which I have referred to several times previously, forms a central part of their theory (in addition to the ideas of Pierre Bourdieu, Theodore Schatzki and Andreas Reckwitz), and builds on his emphasis on the interplay between structure and agency. In addition, their focus on practices as discrete entities, rather than on those doing the practice, reflects the design of the ACE study, which sought to follow the process of the admission, rather than the particular decisions of any one individual ([348]p.126).

The following discussion is designed as neither a comprehensive exploration into Shove et al.’s [348] theory, nor a critical appraisal. Instead, I use it as a frame of reference to help better understand the contributing practices of admissions, and to tie together the ideas considered earlier in the chapter. I begin by reviewing the precariousness of home at the end-of-life, the limited scope of ambulance practice in end-of-life care and the contradictions within current conceptions of hospital. Next I consider the many practices which have contributed to the conception of ‘inappropriate’ admissions, and conclude by establishing the importance of planning for understanding the case-patients’ admission.

2.2 Dying at home

Practices involve the integration of three elements; materials, competencies, and meanings [348]. Materials encompasses both tangible items – objects, tools, the body – as well as the less the observable like infrastructure ([348]p.23). Competencies includes understanding and practical knowledge ([348]p.23). Meaning refers to emotions and motivation, including awareness of the symbolic significance of participating in a practice ([348]p.23-24). Practices are the product of the repeated linking of these three elements, as demonstrated next when thinking about home.

Dying at home is a practice. Appropriate death at home required significant materials according to the interviewees. As well as apparatus, for sleeping, moving and being cared for, being cared for at home required paper documenting decision-making to restrict some actions (such as resuscitation orders) and facilitate others (such as anticipatory drug prescribing) because qualified healthcare staff were not present at all times. The practice of dying at home ‘well’ required know-how; most significantly from family carers in how to provide care for the dying, but also from medical and nursing practitioners in
how to apply their care to the home setting, and to educate family carers in how to perform it. Home must also be understood as an acceptable and desirable place to die, and required the tying of ideas of familiarity and comfort to the normative concept of a ‘good death’ (e.g. Box 2).

Change to any of the elements changes the practice ([348]p.7, 34). For instance, the invention of the syringe driver by Dr Wright in the late 1970s, which facilitated safe and continuous delivery of medication outside of the hospital setting [376, 377], in addition to earlier drug innovation in palliative pain relief [21], allowed home to be an environment where symptoms could be more easily controlled, thus changing what was meant by dying at home. The absence of elements has consequences too, preventing the practice of dying at home occurring in the same way ([348]p.45). The consequences of the lack of care are well recognised, such as the problem of unskilled informal carers who cannot ‘cope’ with caring, or insufficient medical equipment in the community to accommodate home care (chapter 6, sections 2.2, 1.2.1). For the case-patients, the material absence of sufficient nursing was a particular problem, especially where it meant that patients’ symptoms were not appropriately controlled or where their hygiene was compromised, in turn contravening the expectations of a ‘good death’ at home (chapter 3, Box 2).

Inadequate knowledge held by family carers of how to provide end-of-life care certainly made continuing to keep a patient at home more difficult, especially when compounded by insufficient nursing care, but equally relevant was the knowledge of healthcare providers on how to successfully arrange additional care for patients (chapter 6, section 3.3.2). Of perhaps greater relevance was where patients or their family did not recognise home to be a desirable place to die, such that they sought refuge in the hospital (chapter 5, section 5.5).

When practice occurs, the elements are integrated, or linked, together, in turn facilitating the creation of new elements ([348]p.120). Since continued renewal of links and elements are critical for the persistence of the practice, practices require practitioners – people – to continue to perform the practice in order for it to persist. The practice of dying at home persists, in part because of the repeated claims that home is where patients wish to die, emphasising the meaning of dying at home, whilst associated practices that follow from the policy interest in it facilitate the materials and know-how necessary for it to occur. End-of-life care documentation completed by patients and community staff, for instance, directs and formalises patient wishes about their dying
and in turn establishes an impetus for practitioners to meet this wish by arranging equipment, care and preparing carers to care for patients.

It is apparent that these practices, and many others, co-depend on each other. In doing so, the practice of dying at home becomes a ‘bundle’ of practices ([348]p.18). An important dependent relationship is with the bundle of practices about hospital dying, which contributes to the meaning of home through a dichotomous normative construction of home as ‘good’ and hospital as ‘bad’. For instance, policies relating to increasing care in the community plausibly contributed to the infrastructure of community provision and the desirability of home, but did so in part by emphasising that hospital care is not always necessary or desirable ([378] chapter 3, section 1.3). Similarly, the emphasis on choice in end-of-life care policy created the idea that a death at home was the enactment of patient choice, in tandem with the idea that dying in hospital meant the denial of choice. Co-dependency can also occur across multiple practices too. Thus the presumption that a death at home is less ‘medicalised’ than one in hospital echoes arguments made during the establishment of the practice of hospice care, whereby the impetus for a more holistic approach to dying was the poor deaths occurring in hospital (which in turn can be tied to earlier conceptions of inadequate hospital deaths) (chapter 3, section 1.1.1).

2.2.1 After home: GP, ambulance and A&E practices

In situations where the practice of home death became interrupted, as occurred with many of the case-patients, it was typical for either GPs or ambulance staff to become involved, and frequently both. Here, both practitioners carried their own practices with them, and were limited in their ability to reframe the scenario and reinstitute the practice of home death without first involving a transfer of the patient to hospital.

GPs instigated hospital care where it was apparent home care was considered untenable for the patient, often when dying practices did not match the scenario found at home, sometimes because of insufficient care materials (section 1.6). In this situation, their ability to ‘carry’ the practice of care at home was compromised, and they therefore instead sought alternative care for the patient in hospital. Here, the hospital as a recognised institution for emergency provision (section 1.5) could facilitate aspects of the practice of dying not fulfilled at home (section 2.2).
The practice of ambulance care in the home was often poorly suited to the care of dying patients at home (chapter 7). The ambulance staff were knowledgeable about emergency care, not palliative care, and knew how to safely and quickly transfer patients to hospital, rather than how to keep them at home. Meaning was similarly attenuated towards emergencies and hospital care, and matched the resources affiliated with ambulance care: a vehicle suitable for the urgent transfer of patients, portable diagnostic equipment and direct access to the hospital. Whilst ambulance staff strove to adapt this practice to that of dying care, they did so against considerable challenges.

Materially, the absence of end-of-life documentation significantly hindered the ability of staff to keep a patient at home (chapter 7, section 1.2). Lack of access to quick medical advice and nursing resource (excluding the hospital) also limited their involvement. The acceptability of keeping a patient at home was challenged both by an emphasis on patient survival, and by general ideals about comfort and a ‘good death’ where the home environment was recognised not to meet them (chapter 7, sections 2.1, 2.2.2, chapter 6 1.2.1). It is thus unsurprising that the practice of ambulance care overrode that of dying at home.

Moreover, the practices which the ambulance staff carried reflected the wider social context in which they were occurring [348]p. 135). Thus the limited professional scope that ambulance staff had was realised in their restricted access to community care and limited ability to successfully navigate contradictory policies (section 1.2, chapter 5, section 4). Relatedly, the relative exclusion of ambulance care from early end-of-life care policy (chapter 5, section 2.2.2) is likely to have had an impact on the knowledge and meanings ambulance staff held about palliative care.

Once a patient had been transferred to hospital, the dominant practices of A&E inhibited consideration of an immediate transfer back to home. These included bureaucratic practices, such as the impetus for registering patients, and clinical practices associated with the early commencement of medical treatment and including a strong normative emphasis on providing care (orientated towards the acute-care patient but still applied to those at the end-of-life) (chapter 5, section 1.1). Together with much broader practices related to policy targets (specifically the 4-hour wait) meant that a patient was admitted and encompassed within the institution of the hospital (chapter 5, section 1).
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In this way, the case-patients care can be recognised as an amalgamation of practices related to dying at home, general practice, ambulance care and the hospital which, in their situation was broadly directed towards in-patient hospital care. Not addressed however is the paradox that hospital was also well established as an institution to be avoided in general end-of-life care practice. I therefore turn next to consider how hospital could be transformed into an acceptable component of dying practice.

2.3 Why a hospital death is a bad death

The material and knowledge components of hospital dying were similar to those of home practice, but were often understood differently. Hospital equipment and care were not always recognised to be either appropriate or designated for end-of-life care use, reflecting that dying in hospital was not recognised to be a significant goal of Meadowbridge by interviewees (see section 1.3). Similarly, the knowledge required to care for the dying was often designated as specialist information, and hospital interviewees typically did not recognise themselves to be competent in palliative care (chapter 5, section 2.1). The meaning of the practice of dying in hospital was distinct from home care, and was broadly unfavourable (chapters 3, 5). The meaning of dying in hospital was shared with other healthcare practices whereby acute care provision (encompassing for instance an emphasis on survival, aggressive treatment, and impersonal care) was emphasised by hospital interviewees and in policy justifications of the reduction of ‘inappropriate’ admissions (see chapter 3 section 2.2.1, [348]p.84).

Together, these elements made the practice of dying in hospital counter to the conception of a ‘good death’ as recognised in policy.

However, hospital was considered to be a more acceptable practice when death at home did not match the ideal of an expected good death. In this situation, meanings inherent within the idea of acute care (e.g. hygiene, efficiency, provision) were prioritised by interviewees, in addition to the adequate provision of materials and knowledge recognised to be important for end-of-life care.

The scope of meanings associated with the practice helps to explain the divergent references to hospital by interviewees. Hospital could both be a poor site of death and also a refuge, because both these ideas were inherent within the practice of dying in hospital, and it depended on which elements were emphasised by interviewees. Such contrast was not inconsistent, given that the hospital, as a complex of practices has many different meanings attached to it. In turn, this explains why staff struggled to
categorise end-of-life patients in hospital, and why community staff expressed reluctance to facilitate transfers to hospital, despite the patients’ need for care. The hospital is likely to have meant different things to different practitioners, and was contextualised by the particular practice being prioritised.

### 2.4 Planning: Why admissions are inappropriate and how this occurs

End-of-life hospital admissions occur at various levels, and can be analysed accordingly (p.39). One way is as above, where the practice of end-of-life admissions can be considered as a series of discrete practices—home, ambulance, hospital—which interlink to constitute its occurrence (p.7-8). Another way to view admissions is as a bundle of practices, which constrain and enable one another, such as how practices about dying at home, and dying in hospital co-depend on each other to create the practice of admissions, as I discussed earlier. Alternatively, admissions can be understood as part of a constellation of practices. Here I use the practice of planning to understand how end-of-life admissions are problematic within end-of-life care policy.

End-of-life care planning is recognised as a central task in end-of-life care provision, and has contributed to the concept of ‘inappropriate’ admissions. This occurs directly through the focus on place and choice (chapter 3, section 1.2.2), whereby hospital is condemned as an undesirable place of death, since admission in this instance cannot be pre-arranged (chapter 3, section 1.2.1). Planning was also tangibly tied to the evaluation of the case-patients’ admissions, since the absence of known community planning negatively contributed to the appraisal of the patients’ admission by interviewees (chapter 5, section 3.1, 3.2.1). The appraisals of admissions were also related to patients’ presenting symptoms, and here too planning framed these through the classification of dying trajectories. For end-of-life planning to be effective, dying must be predicted and categorised (chapter 3 section 1.2). Recognised and accepted trajectories of dying consequentially allow for the categorisation of symptoms as either ‘expected’ or ‘unexpected’. Where patients’ symptoms were classified as ‘expected’, their admission was negatively considered, since it was presumed hospital could have been prevented had more effective planning occurred. Conversely, where patients’ symptoms were classified as being ‘unexpected’ and thus outside of the bounds of predicted needs, admissions were more positively viewed, such as where patients had deteriorated more quickly than expected, or where patients had ‘unpredictable’ symptoms.
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Practically, planning affected the likelihood of hospital admissions. The (un)availability of care resources was critical for many of the case-patients’ admissions to Meadowbridge, since hospital was used as a place of safety where care in the community could not be sought (section 1.5). The practice of planning was used to facilitate care, whereby interviewees described arranging care to meet the patients’ predicted dying trajectory. However, where patient symptoms deviated from what had been predicted, staff struggled to arrange additional care. This demonstrates not only the tangible consequence of planning (such that ‘inaccurate’ planning increased the likelihood of admission), but moreover points to the allocation of care by planning, such that care was difficult to acquire at short-notice. Whilst this is likely in turn to be influenced by the wider organisation of care-practices beyond end-of-life care, it places a strong incentive on planning.

The emphasis on planning also affected the way in which staff organised end-of-life care, in turn shaping the likelihood of admissions. End-of-life care policy recommended the mechanical organisation of care, but this did not seem to be well-suited to the practice of caring for the case-patients, because of the difficulty staff had in accurately predicting the patients’ dying trajectory and care needs (section 2.4; chapter 3, section 3). Where predictions were inaccurate, it left staff and patients vulnerable to arranging care without support. In practice, community staff adopted an adaptive, organic form of planning which seemed better suited to the ambiguity involved in end-of-life care (section 1.1). However, this approach also contributed to the negative portrayal of hospital admissions, because the lack of documentation and recorded decision-making made it less evident that planning had occurred.

Monitoring is part of the enactment of practice ([348]p.100), and in planning, accentuated the idea that dying in hospital was not a desirable place of death, thereby contributing to the negative portrayal of admissions. Place of death is a valuable metric in a field with limited alternatives for measuring output (chapter 3, section 1.2.2), and hospital is a key category within the metric. Hospital, by not being ‘plannable’ is necessarily poorly considered (section 2.3). The continual monitoring of place of death, through regular reporting of data, therefore continually emphasises the rhetoric that hospital is a poor place of death. Evidence of this was seen in how healthcare staff reviewed their care of patients, such that those involved in planning often concluded that a death in hospital was a failure of their care, whilst hospital staff typically did not value
the care they provided to case-patients’ who were considered to have an ‘expected’ trajectory.

More broadly, planning also dictated the practice of patients and their carers. End-of-life care planning is initiated by end-of-life care conversations, where the participation of (typically) community staff, patients and their carers, is encouraged (chapter 3, section 1.2.2). These conversations consequentially contribute to the labelling of patients and their carers who do not wish to participate, or to discuss their preferences in these conversations as deviant by staff, since their apparent reluctance to participate obstructed the planning process (chapter 2, 4.1; chapter 6, 3.1.2). More abstractly, they also affected the ordering of the patients’ time whereby conversations could occur ‘too early’ or ‘too late’ in a patients’ trajectory.

Planning thus is a ‘dominant project’ in the ‘complex’ of end-of-life care: fundamentally defining the terms of end-of-life admissions with consequences for the meaning, organisation of resources, and the knowledge necessary for end-of-life care ([380] cited in Shove et al. [348] p.79). Planning is both a distinct practice (section 1.1), with clear lineage to ideas of bureaucracy and rational management of work through mechanical organisation, but also affected many levels of practice concurrently. This occurred not only individually, by healthcare staff in their provision of day-to-day care, but also institutionally too, through policy decisions about the need to organise end-of-life care ([348]p.135). In short, the practice of planning fundamentally shaped the landscape of end-of-life care for the case-patients.

2.4.1 Conclusion

Within this chapter I have explored admissions from a variety of angles. I have considered the difference between how end-of-life care is intended to be organised, and how it was for the case-patients, in order to better understand how they came to be admitted to hospital. I assessed why ambulance staff had limited professional authority to prevent admissions, how family carers managed to keep supporting patients at home, and the consequences for hospital staff of end-of-life patients being in hospital. I have explored why hospital was sought for care, despite being an ‘undesired’ place of care, and why community staff facilitated admissions. I concluded by considering how home could become a place of care, and the wide-reaching impact of planning in end-of-life care.
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From this discussion it is apparent that ‘inappropriate’ admissions are an inherently social phenomena, reflecting ongoing practices to do with planning, hospital care, a ‘good death’ amongst others. The value judgements placed on end-of-life admissions reflects this social context, but inaccurately condenses this complexity into binary categories which do not explain the scenarios which led to the case-patients admissions.

It is clear too that the idea of ‘inappropriate’ admissions has become interwoven into contemporary UK conceptions of dying, recursively reinstated through the swathes of end-of-life care policy documentation and the corresponding practices which have emerged from these. The way in which these admissions are viewed therefore seems unlikely to change soon, despite the apparent inaccuracy of the rhetoric used. If fewer end-of-life admissions are to occur however, something must change, and in the concluding chapter I consider what this might be, and ways in which this could be achieved.
"So broadly my view is that there must be better ways to assess whether someone has a good death than their place of death. It may be a factor but actually most people I would imagine seek peace and comfort in their dying relative rather than the postcode in which they die at."

(05, 5)
Chapter 9

Inappropriately described: hospital admissions at the end-of-life

End-of-life admissions represent the culmination of a series of social practices enacted by patients, family and healthcare staff and others. In this concluding chapter I review these practices to consider what can be learnt about end-of-life admissions from my research, contextualised by reference to contemporary scholarship on end-of-life care and admissions.

To do so, I begin by answering the research questions set in chapter 1 with material from chapters 2-8. I address next the limitations of the study, from which I then consider the implications of my research for practice and policy. I conclude by challenging the inappropriate normative labelling of end-of-life admissions.

1. Understanding ‘Inappropriate’ admissions

In this thesis I have sought to understand the context of end-of-life admissions, and to explore the ways in which they occur. I have done so through a literature review, appraisal of the construction of the rhetoric about ‘inappropriate’ admissions and an analysis of the accounts of healthcare staff and next-of-kin involved in nine end-of-life admissions to Meadowbridge, with each revealing more of the tangled practices of admissions.

1.1 Do patients prefer to die at home?

The systematic review we conducted showed it was not known where most patients in the UK want to die. This conclusion jars with much end-of-life care rhetoric which is centred on home and meeting choice, and contributes useful evidence to a growing literature which critiques the presumption that home is where most patients want to die (see for instance [26]). Accounts from interviewed healthcare staff and patients’ next-of-kin reflect this finding, with benefits ascribed to both home and hospital deaths such that choices for one location or another were rarely wholly categorical or positive (see also [17, 32]).
This challenges the presumption that end-of-life admissions are undesirable because they contradict patient choice for place of death. Furthermore, whilst the review produced little evidence to support the idea that patients want to die in hospital, the recognition of the nuances involved in preferences for place of death allows space for hospital to be an acceptable place of death [50, 63], if not always a preferred place of care [68].

1.2 What contributes to the ideas that hospital is a bad place to die, and end-of-life admissions are a problem?

The problematic conception of hospital in contemporary end-of-life care rhetoric seems likely to have been structured by prior conceptions of earlier forms of hospital practice, where dying often too occupied a difficult position, such that recognised end-of-life patients could be excluded in hospital admission practices and where hospital deaths which did occur were often acknowledged to be inadequate. More recently, justifications for hospice care and the emphasis on place and choice in end-of-life care have acted to sediment the presumption that deaths in hospital are poor, together with widely reported scandals of deficient hospital dying care.

Amidst this concern has been a focus on end-of-life admissions and the proportion dying in hospital, tied to demographic and epidemiological changes which are predicted to increase the likelihood of deaths occurring in hospital [381]. The condemnation of end-of-life admissions seems tied too to earlier policy interest in general hospital admissions, which demonstrated a presumption that admissions could be prevented and provided a rhetoric of cost to explain measures to address them. Also relevant is broader trends of increased community-based provision and a pervasive belief that end-of-life care can be managed with sufficient planning. Accepting the tangible differences that can and do exist between hospital deaths and those that occur in hospice and community settings, it is implausible that the above ideas have not contributed to the negative construction of end-of-life admissions.

1.3 What are the views of healthcare staff, patients and families about end-of-life admissions?

All healthcare staff groups recognised that hospital was not where ‘good’ deaths typically occurred, shaped by the apparent orientation of the hospital towards non-dying care, and which negatively coloured how staff viewed the care they provided to patients, the quality of the patients’ death, and the prior care of others.
Concurrently however, hospital was recognised by all participants as an emergency place of care, reflecting the practice of community staff relying on hospital where patients needed care which was unavailable easily elsewhere. In this context, patients were admitted to the hospital and the environment was recognised to offer distinct benefits by patients, family and healthcare staff to home end-of-life provision. As a consequence of the multi-faceted roles of the institution of the hospital (reflecting the many practices that the hospital was involved in) staff struggled to conclusively categorise the patients’ admission as either (in)appropriate or (un)avoidable.

1.4 What are the dynamics of the processes leading to end-of-life admissions in the community?

For dying to occur appropriately in the community, home had to be adapted to accommodate health practices. Family, supported by community healthcare staff, were central, ensuring the smooth transition from ‘home’ to ‘home-as-a-place-of-care’, and facilitated its continued success by instituting informal care practices. End-of-life care planning practices advocated in policy were important in this process, but had to be modified by community staff to be compatible with the individual patient’s changing symptoms and needs.

Difficulties in any of these adaptations challenged the likelihood of home death. If as a consequence patients’ needs were not sufficiently met, the patients’ transfer to hospital was often inadvertently enabled by the organisation of community care practices. The apparent emphasis on advance allocation of resources was often incongruent with the urgency of the patients’ needs. In such instances, well-established practices for gaining emergency healthcare were directed towards hospital, which for the healthcare staff involved in the case-patients was recognised as the default place of care.

1.5 What are the dynamics of the processes leading to ambulance staff facilitating end-of-life admissions?

When called to the case-patients, ambulance staff instituted familiar practices in transferring them to hospital. Whilst this was often enacted with significant hesitation, the patients’ condition was either recognised to fulfil criteria for urgent hospital transfer, or in the context of their home care, contravened that accepted for home dying. The transfer was facilitated by significant obstacles for the ambulance staff to facilitate alternative community care, including limited staff authority, insufficient evidence of end-of-life practices by other healthcare staff, and restricted access to available support.
from other healthcare groups. As a consequence, hospital was considered a default place of care.

2. Limitations and relevance

These findings are specific to the admission of nine case-patients as recounted in thirty-three interviews with healthcare staff involved in their care. The significance of the conclusions which can be singly drawn from this sample must therefore be modest [382], and contextualised by the following limitations.

The research on which my findings are based was of a specific cohort of patients, setting and time-period, as identified in chapter 3. These factors necessarily contextualise the findings that I have drawn. The case-patients for instance were white British, had been cared for previously at home or in a care home, with family support present to varying degrees. These characteristics may have contributed to the likelihood of the case-patients not dying in hospital [383], and together with other features mean that the individual reasons for their admissions are not necessarily representative of individuals in other situations admitted to hospital shortly before death. The healthcare staff I interviewed were predominately doctors or ambulance staff, and in caring for Meadowbridge patients, were working within a system that performed comparatively well according to current palliative care measures (chapter 3), and thus may have had a different perspective of admissions to those working elsewhere or in different occupations. Similarly, the admissions occurred in the wake of the furore of the Liverpool Care Pathway when hospital end-of-life care practices had been particularly scrutinised, which likely affected not only who I recruited for the study (chapter 3), but also the topics interviewees stressed in the interviews. Furthermore, my role as an interviewer and an analyst will inevitably have framed the accounts I conducted and the analysis I undertook of their accounts— as a sociologist, non-clinician, and student (chapter 3) - and in this sense the findings are unique to this study.

However, it is also apparent that the accounts of admissions I drew on to reach my conclusions match the experiences recorded by others, with clear similarities with my empirical findings and the conclusions of others. Thus for instance, the relative irrelevance of the descriptor ‘inappropriate’ for end-of-life admissions has been found by others [10], argued for in part because hospital is recognised to be a place of safety for patients [16, 384]. Similarly, the use of hospital as a default place of care is reflected in recent research on older adult emergency hospital admissions, which also finds that once
admitted it is difficult to discharge dying patients from hospital, and highlights the significant role of the ambulance service [385]. Together with other similarities highlighted in chapters 5-7, this suggests relevance of the findings beyond Meadowbridge.

The study findings also have a wider significance beyond corroborating the findings of others, elicited through the use of sociological concepts. By focusing on the organisational goals, institutional practices and other ways in which social practices compete, contradict, and enable others – in short the structure and agency of admissions – abstracts the analysis. It means that findings follow not from the nine admissions as they occurred individually, but from the (socially constituted) structures which were present across these admissions and which facilitated their occurrence [386]. As a consequence, the findings can be considered to exist beyond the nine admissions, Meadowbridge and the healthcare staff interviewed [386].

Therefore, where similar circumstances exist elsewhere to those identified of the case-patients, admissions are likely to occur in similar ways. It seems likely admission practices elsewhere will be comparable for instance where end-of-life planning practices are mechanically ordered, or where there are competing goals in the ambulance service between the priorities of acute care versus the needs of end-of-life patients. However, caution should be asserted before presuming that in all situations which appear to match the practices which contributed to the case-patients care will admissions occur in a similar way [262] because of the scope of individual agency [382], and the personalisation of social practices to the specific resources available. For instance, even amongst healthcare groups it cannot be presumed that the same issues which were experienced in caring for the case-patients will be wholly applicable, because of variation within the group. For example the ambulance service nationally is recognised to be made of many heterogeneous local ambulance services [331], and thus it is possible that different regional groups will have different end-of-life practices.

3. Policy and practice suggestions to address ‘inappropriate’ admissions

Suggestions for addressing hospital admissions must be contextualised by recognition that admissions are the emergent product of a series of social practices and are not a single coherent static phenomenon. Whilst the specific combination of practices, and their components, are likely to vary according to the limitations addressed above, their
number, interconnections and their evolving nature mean that the broad practice of admissions as an accumulation of them will always be to an extent uncontrollable ([348] p.144-146). This does not mean that attempts to change them will be unsuccessful, but that any attempts to do so will occur within a context of on-going practice, where any single change will not occur in isolation ([348] p.144-146). An awareness of this seems necessary for any attempts to change admissions to be successful, together with an orientation towards a trial-and-error approach, in order to review how practices are changing and to monitor unintended consequences ([348]p.145).

The form of this change seems likely to take one of two forms: 1) of accepting that admissions will occur and modifying the hospital environment in order to make it more acceptable for end-of-life care and death, or 2) changing the practices such that hospital is not sought, by providing a combination of a) an alternative to hospital and b) more resources to facilitate a patient staying at home. A realistic approach maybe to adopt both one and two, with change likely to involve influencing: the range of elements necessary for admissions-related practices; the way these practices connect with each other; and how practices are reproduced and persist ([348] p.146).

In the next section, I make suggestions for what these changes may be. None of these suggestions should be acted upon on the basis of this thesis alone. Local research would need to be conducted first which surveyed the particular patient population and their reasons for admission. Ideally this research would involve a more comprehensive sample than the ACE study, including the perspectives of community nurses and care home staff, and would adopt a similar emphasis on structure, agency and practice in order to elucidate the particular nuances of admission practices in the area.

3.1 Address hospital care

Hospital occupies a significant place in end-of-life care, with admissions where patients die shortly afterwards accounting for over 30% of all deaths ([4], chapter 3, section 1.4.3). This prevalence, together with demographic and epidemiological trends towards hospital admission suggest that end-of-life admissions are likely to remain a ubiquitous part of UK end-of-life care provision.

My first suggestion therefore to addressing end-of-life admissions is to recast them as appropriate admissions. This would require acknowledging the important and continuing role of hospital and would mean addressing efforts towards improving the end-of-life provision that occurs within it. Encompassing hospital more explicitly within
future end-of-life care policy would help to address the first part of this requirement, and would be necessary for the practical changes suggested in the second part.

If care of the dying is to be accepted as a legitimate role of the hospital, the poor reputation of hospital care must also be addressed. The problems with hospital care at the end of life are well-known (chapter 4, section 2.2.1). Changes to tackle these problems would need to be evidence-based in order to ensure that care was orientated not only to the patients’ needs, but also to reflect the demands of the hospital and input from the hospice sector is likely to be particularly pertinent to understand how end-of-life care can be successfully provided in an institutional setting. Recognition that dying both occurs and is acceptable seems an important focus of amendments to hospital care, from which, for instance, stopping unnecessary treatment and interventions could be instituted (cf [329]). Changes are likely to build on existing practices performed by hospital interviewees, including for instance reducing in-hospital transfers, mediating the noise and bustle of the hospital by placing patients in quieter areas, and curbing aggressive medical treatment. Comprehensive, general palliative care training for all healthcare staff would complement this approach. Less relevant would be making changes to hospital to imitate the home environment, because patients still sought the safety of it in dying, despite recognising it as a distinct environment to home.

These suggestions are counter to current policy trends which are orientated towards reducing hospital demand, both in terms of healthcare provision, and end-of-life care. Whilst they echo calls both in geriatric medicine [270, 364] and end-of-life care [13], and may provide a more economical resolution to end-of-life care than increasing community-based provision (chapter 3), the current unpopularity of hospital may challenge the success of such attempts. More feasible attempts to address ‘inappropriate’ admissions therefore may lie in the community, which I explore next.

### 3.2 Changing admissions

Preventing the occurrence of hospital admissions requires that practices for end-of-life care are re-directed away from the hospital. I begin by considering the importance of the community hospital in preventing acute admissions, before discussing changes that could occur in the community to allow more end-of-life patients to die at home, concluding by considering the necessary amendments to the planning process to facilitate this.
3.2.1 Care in the community hospital

A contemporary imagining of the community hospital seems a conceivable alternative to care sought in hospital. Small, local hospitals which provided a similar level of nursing care to hospitals like Meadowbridge, but without the emphasis on acute care provision, could provide the safety and refuge sought for the case-patients in the hospital by healthcare staff and families. Current research suggests the community hospital to be a place more acceptable to end-of-life patients than general hospital [387], offering the familiarity of local surroundings (and reduced travel for family carers) [388], and with the resources and professional expertise necessary for appropriate end-of-life care provision [389]; thus resolving many of the problems recognised with general hospital end-of-life provision (chapter 3).

Wide-scale use of the community hospital in this way would however require a reframing of the community hospital, which typically focus on rehabilitative care for patients discharged from hospital before returning home [388]. Furthermore, adoption of this suggestion would need to overcome significant political pressure, given current predictions for further hospital closures through the current NHS Sustainability Transformation Plans [390, 391]. However, the commitment by Simon Stevens at the start of his term as NHS England CEO for more emphasis on smaller hospitals identifies some political will for this move [392], particularly if it could be coupled with evidence of financial benefit. On a general basis, institution-based care seems to offer a more cost-effective way of providing palliative care to a growing proportion of dying patients than similar provision delivered to individual patients at home, and cheaper in a community hospital than the resource-intensive death recognised to be provided in acute hospital (chapter 3).

3.2.2 Care at home

An alternative approach to preventing hospital admissions would be to meet the care needs of patients at home. Community care for patients in circumstances similar to the case-patients would need to be rapidly available, reliable, and comprehensive, to resolve the problems experienced by healthcare staff interviewees. Meeting this requirements seems likely to require increased capacity of provision recognised as difficult by staff (out-of-hours medical care and community nursing), and could be complimented by increased availability of social care provision [385] and hospital-at-home services [393] in order to prevent admissions. These changes would support the day-to-day care provided
by family carers, as well as formal care provided in care homes and other settings. A need for increased in-patient hospice provision was recognised by interviewees, and would provide an acceptable community-based alternative to hospital admission, but would require a reorientation of palliative care provision, given its present focus on specialist palliative care needs [125].

However, increasing provision may be too costly to achieve, particularly in a context where it is unclear whether a decrease in hospital admissions would lead to tangible savings intended for reinvestment in community care (chapter 3, section 2.2.3). Social care is recognised to be in a situation where its sustainability is challenged [394]. Additional community health funding seems unlikely given recent historic commitments to extend provision in the General Practice Forward View [395], especially if it occurs at the expense of hospital funding given the current financial crisis [396]. Presuming however that additional capacity could be funded, changes would be necessary to the way in which care is organised, and I turn to this next.

3.3 Planning

Modification of the way in which planning occurs for end-of-life patients seems necessary, regardless of how admissions are addressed. Adapting the planning process to make it more flexible and in keeping with the organic organisation approach adopted by healthcare staff for the case-patients seems a plausible approach to facilitate more deaths occurring in the community. Planning would ideally encompass the inherent uncertainty of dying and care needs, the ambiguities involved in patient preferences and be able to accommodate changes – whether of care needs, healthcare provision or family caring – to allow healthcare staff the flexibility needed to quickly arrange care in order to resolve situations which for the case-patients lead to their admission. Current advances in electronic data-sharing would help facilitate the collaboration necessary for such a flexible approach and encourage planning to be recognised as an ongoing process because of the relative ease of amending records [397].

It would also be desirable to change the focus of planning from place of death to a more holistic consideration of patients’ care needs and where these would be best met at different points in their dying trajectory. Although such changes seem unfeasible whilst place remains the most practical outcome measure for end-of-life care, they could lead to significant improvements. In addition to allowing a greater focus on non-place related priorities for patients [50], this approach seems likely to benefit staff and address the
apparent ‘failure’ of end-of-life care when a patient had died in hospital, a judgement which masked significant prior input.

3.4 Better hospital care, community provision and planning

For admissions to be robustly addressed, an approach which combined all of the above suggestions seems pertinent. Whilst more community care would help prevent the need for hospital admissions, whether acute or community, it seems implausible that this need could be entirely eradicated. Furthermore, many aspects of end-of-life care are either unpredictable, or depend on people who are new to end-of-life care – either as patients or family carers – and therefore whose needs, and capacity to care can never be wholly predicted or planned for. Therefore, increased community capacity plausibly would allow more patients to die at home. Community hospitals could meet the (non-acute) patient needs not wholly met by community provision. Modifications to the acute hospital would allow the hospital to continue to act as the ultimate safety-net at the end-of-life and provide care considered more appropriate to the dying patient, including to those patients whose admission could not have been predicted in advance, dying patients with acute-care needs, and emergency patients.

4. Conclusion

The admissions of the case-patients to hospital were not ‘inappropriate’. Normative descriptions of the case-patients' admissions had little explanatory power, and contributed to the condemnation of hospital as a place of death. They devalued the significant care provided by healthcare staff in the community and hospital setting and inaccurately simplified differences between ‘good’ deaths at home and ‘bad’ ones in hospital.

The admissions of the case-patients represent the best attempts of staff to navigate the tangled practices of end-of-life care, which they both created and which constrained and enabled their action in providing care to patients. Hospital was conceptualised differently for each of the case-patients by interviewees, but common to each was its role as a place of safety in dying, making hospital care at the end of life an important part of contemporary UK provision.
For instance, where the cost of hospital admissions is estimated within the EOLCS, a caveat follows which states that some of the deaths included in the cost will be unexpected, implying that unexpected admissions are more appropriate than those where deaths were expected [1] p.150.

As a care quality commission report on care homes [11] states “a death so soon [within 3 days] after entering hospital could mean that the admission was unnecessary; the person may have been reaching the end of their life and could have been cared for in their care home”(p.101) whilst “if a person spends a long time [greater than eight days] in hospital before dying, it could indicate that the trust’s arrangement for end of life care and its links back to social care services are poor”(p.102).

In England, in the financial year 2014/15, 232,854 (47%) deaths occurred in hospital of a total 491,378 registered deaths. 66,470 hospital deaths occurred within three days of admission. (Data on deaths within three days of admission was calculated from data requested from, and provided free of charge by, National End of Life Care Intelligence Network (reference HS161025)).

It is hoped that this metric will be replaced when new metrics to measure progress against the NHS mandate are developed by June 2018 [5].

A BA in Politics and Sociology, and an MPhil in Educational research methods.

Currently, the percentage of hospital deaths is used, and previous iterations of the indicator have used the inverse measures of percentage of deaths at home, and deaths in usual place of residence. Common to each measure is the emphasis on patients not dying in hospital, and the presumption that home is where patients want to die.

Hospitals for ‘incurables’ had occurred prior to this (St Guy’s Hospital in London for instance was founded to provide care for ‘incurable’ or ‘insane’ patients in 1725) but these were the first examples of medical establishments solely for dying patients.

The second paragraph stated: “patients want to [...] be enabled to die in the place of their choice, often their own home”([90] p.3).

The Programme aimed to decrease the numbers of patients who died in hospital shortly after admission but who had wished to die at home, or had been transferred in their last week of life from a care home [91].

The strategy focuses exclusively on end-of-life care for adults. A separate strategy for children was published in 2008.

This encompasses residential, care and nursing homes which for some residents, but not all, is their long-standing home.

Turton [18] estimated that 48 official reports and documents have been published on the subject for the period of 2008 to 2015, and subsequently at least five more have been published.

The bundle was developed in 2010 to improve end-of-life decision making with hospital patients whose prognosis was uncertain but for whom there was a chance they may die in the near future [101].
In the 50 page document 'home' is used thirteen times, seven of these in the reference list, one as 'care home', and another as 'homeless.' There are six mentions of the word 'hospital'. Of these, two are in the reference list.

For example, Neuberger, Guthrie [105] has five separate references to the phrase ‘tick-box’ or a derivate of it.

Radio interview exchange between the news reporter John Humphreys and Susan Dewar, community nurse and independent NICE guideline committee member:

John Humphreys: “Listening to you [describe the guideline], it just sounds like common sense

Susan Dewar: “it is, it is common sense, very much so”

Humphreys also started the story with the preface: “People who are dying should be treated with respect and compassion you would hardly think it needs saying in a civilised society, but apparently it does” [116].

Social care provision is generally not covered by the NHS, except for patients who are in receipt of NHS Continuing Healthcare funding, which is needs-tested and provides relevant hospital care outside of hospital [118]. Local-authority social care provision is available for those ineligible but still assessed as needing care [119]. This care is means-tested and if care recipients exceed this capital threshold they or their family and friends must pay for the care themselves [120]. Recipients of local authority support receive a ‘personal budget’ to pay for social care, which can be ‘topped up’ by the patient or others in order to receive more expensive or extensive care [120].

Nurses who specialise in palliative and end-of-life care and who can coordinate care on behalf of the patient.

Data was calculated from data requested from, and provided free of charge by, National End of Life Care Intelligence Network (reference HS161025), using data from Hospital Episode Statistics with the permission of NHS Digital.© 2016.

Data retrieved from Office for National Statistics [12] licensed under the Open Government Licence v3.0 © Crown Copyright

Data from 1963-1973 was calculated from [131]. Data from 1974-2004 was calculated from data requested from, and provided free of charge by, Office of National Statistics. Data from 2004-2014 was calculated from data from [132]. Data from 2015 was calculated from [133]. All data is licensed under the Open Government Licence v3.0 .

E.g. [134] p.4.


End-of-life hospital admissions are a ‘key element of expenditure’ of end-of-life care ([1]p.15), with each admission episode estimated to cost £2506 ([128] p.17).

[1] p. 11, 33, 61, 64, 88, 94 and [8].p. 5, 6, 18, 54.

Admissions are described as something which can be ‘prevented’ in p.12, 20, 26, 31.


Taken from Barker [145] and contains Parliamentary information licensed under the Open Parliament Licence v3.0.

*Includes babies born in hospital ** “there were 18.7 million FCEs recorded within the HES [Hospital Episode Statistics] APC [Admitted Patient Care] data set, representing an increase of 3.1 per cent from the previous year. Of these episodes, 15.9 million were
admission episodes (the first episode in a spell)”  Data taken from [151]. Licensed under the Open Government Licence. Contains Copyright © 2015 Health and Social Care Information Centre. Re-used with the permission of NHS Digital. All rights reserved.

30 Using the same assessment criteria, panels of consultants assessed that fewer admissions assessed could have received alternative care, compared to GP groups.

31 For instance, David Praill, formerly chief executive of hospice UK, stated: “Everyone agrees it’s a scandal that so many people are dying in hospital who don’t want to be there. But it’s also blocking the public waiting list […] so if we can get people out of hospital that don’t need to be there, even if it’s only for the last few days of life, it frees up beds.”([161] p.39).

32 “Dr Mary Turner from the International Observatory on End of Life Care, who was consulted during this research, commented: “It isn’t really about choice, although we’re supposed to have this choice agenda – it is also about saving money. If people opted to die in hospital, that would cause problems, and there is an incentive there to push costs onto the relatives by having people cared for at home””([27] p.10).

33 Although hospital stays have generally shortened [163] due to changes to best practice about bed rest [74].

34 Hospice provision is limited, admissions lasting a mean of 14 days and still predominately accessed by cancer patients [171]. Hospital care is determined broadly by clinical need, with unplanned patient access typically mediated by accident and emergency departments [144]. Dying at home may be difficult if services and informal carer availability are limited [32]. Ensuring care home residents die in-situ can also be challenging [172].

35 The second planned phase of ACE was focus groups with patients, and separately with senior managers and policy makers, to discuss end-of-life admissions and why they occur. The third planned phase was a questionnaire study to be distributed to healthcare professionals, to quantify findings found in the previous phases.

36 It was necessary to seek approval for each of the healthcare staff groups we intended to include in the study. Often this meant several separate approvals for each group for each county they worked from. This geographical spread was because the catchment area of Meadowbridge extended beyond the county borders.

37 Dr Walsh hopes to analyse the dataset collected at the second site in the future.

38 This service enables patients to be cared for in their own home with nurses and healthcare assistants visiting, primarily overnight, to provide care.

39 The MCCD is a legal record of death, and precedes the ‘death certificate’ which is issued by registrars on appropriate receipt of the MCCD. The certificate details both the immediate and underlying causes of death, and other relevant conditions that contributed to it. The certificate must be signed by a doctor who attended the patient in the 14 days of their last illness, which in hospital is the responsibility to the consultant in charge of the deceased’s care. A death may be referred to the coroner where the MCCD is not signed in time or where the cause of death is unclear. In some circumstances such as accidental death or where the cause of death is unknown, the doctor signing the form is legally obliged to inform the coroner of the death [198].

40 The data that these graphs represent was collated from ‘secondary uses service commissioning dataset’ for the Meadowbridge CCG, prepared by the county Public Health Intelligence.

41 My previous experience of conducting interviews was limited to degree research with very specific interviewee groups (teenagers for an MPhil study, and school teachers and
Appendix 1

a researcher for an undergraduate dissertation) and it was the first time I had interacted professionally with medical staff or conducted interviews with people known to be bereaved.

42 Assuming that language is socially created. Neatly complementing Structuration theory, Whorf theorises that just as collective social action creates any language, so too does language as a social structure affect behaviour. [189].

43 Whilst my approach has similarities with thematic analysis, due to the contested nature of the term I am choosing not to use it. For example, Gomm’s definition of thematic analysis delimitates, through a distinction with conversation analysis, interviewee accounts and the construction of actions [253]. As I hope I have shown above, viewing interview talk as both constructed and meaningful is both theoretically possible and desirable.

44 The majority of emergency admissions in England occur through A&E (71% in 2012-3). Fewer patients are admitted following GP referrals (16%), and fewer still through other routes, such as following an out-patients appointment or bed bureaux (13%) [144]. At Meadowbridge, the vast majority of unplanned admissions (whether by ambulance, GP or otherwise) occurred through A&E. Patients were admitted to hospital following an initial assessment and a senior review. They could have been discharged (i.e. not admitted) at either of these assessments, or be filtered to alternative non-hospital services. The separation between A&E and admission to the hospital was indistinct and it was usual for there to be a cross-over between A&E and admission to wards, for instance where a ward doctor had assessed a patient for admission from within the A&E department or where an A&E doctor had accompanied a patient to the ward. The admissions process is similar to that described in [263].

45 Dr Patel completed the senior review for admission, as outlined in footnote 44.

46 For clarity, I refer to each interviewee by their title (as designated in  p.79) and their pseudonym surname. In the case of some next-of-kin this simplifies a more complicated familial relationship but was preferred for clarity. It also necessarily reduces the visibility of gender, despite gendered pronouns, which is a disadvantage. This relative absence of gender does not mean that it is unimportant, but reflects my inability to draw conclusions about biographical descriptors (age and race are also absent) due to the small size of the dataset.

47 Following each quotation I provide a code of two sets of numbers (i.e. x,xx-xx). The first is the interviewees code as listed in  . The second denotes the page number(s) that the quotation is taken from in the interview transcript. This process means that as a reader you can have a sense of at what point in the conversation the quotation topic was covered (most healthcare staff transcripts did not exceed 10 pages), and, where multiple quotations are used from an interview, the order in which they came in. Whilst where relevant I do provide directions in the text about this, it provides you the opportunity to check the sequence of talk [261].

48 An acronym for the Emergency Department, an alternative term for A&E.

49 Throughout this thesis, I use the term ‘family’ to refer to friends, family and others who informally provide care for a patient at home. The term omits the important role non-family members have in caring for end-of-life patients, but is representative of care provision for the case-patients who were cared for at home. Alternatives such as ‘loved one’ and ‘informal carer’ were rejected, the former because it is assumes an affectionate relationship and the latter for the absence of relational ties.

50 The constraints on ambulance staff to take patients to hospital are significant to understanding hospital admissions, and will be explored in depth in chapter 7.
Residential homes for older adults are generally categorised into those providing only personal care, which I refer to as ‘care home’, and those which additionally provide nursing care, which I refer to as ‘nursing home’ [286]. (There are also residential homes in the UK for younger adults and children which typically focus on providing care to those with physical or learning disabilities, including for those who have an acquired brain injury following an accident as well as for mental health problems) [286].

This distinction is often absent in the preferences for place of death literature, and contextualises the findings found in chapter 2. It shows that whilst place of death was important for the case-patients, it was not in the dichotomous way suggested in much of the preferences for place of death literature. In turn, this may help to explain the extent of missing preferences found for patients and next-of-kin reporting patient preferences, who may have felt their preferences did not match with the options offered in survey responses or by healthcare staff.

A term widely used in and outside of healthcare, in this setting I use the NHS definition: care sought between 6pm and 8.30am Monday to Friday, or any time on the weekend [321].

I will refer to all ambulance participants as ‘ambulance staff’. Whilst ‘paramedic’ is a well-known role within the ambulance service, and is a preferred title by the ambulance service to refer to personnel [322], it would be disingenuous to use the term in this chapter, as participants were from different grades of staff. Distinguishing ambulance participants by role is not desirable because it would compromise their anonymity. It would also presume a false dichotomy of experience. Due to the recent changes to ambulance roles, experience was often unrelated to job title such that technicians could have been working in the service for decades, whilst paramedics could be recent graduates. Furthermore, whilst length of service and seniority ameliorated some of the problems I outline, all staff described situations about the difficulty of being a transitioning professional service.

A common synonym for the acronym Do Not Attempt Cardio-Pulmonary Resuscitation order.

In order of increasing seniority, ambulance staff who provide hands-on care include: ambulance care assistant/patient transport service driver, emergency care assistant, paramedic, specialist paramedic [337].

Burns’ and Stalkers’ model was the product of analysis of the practices in the electronics industry. In line with Giddens’ argument outlined in the introduction, it seems unhelpful to exclude theory just because it does not derive from medical sociology, especially when the model is so helpful in understanding the case-patients admissions. Furthermore, the use of learning from the manufacturing industry to healthcare is not novel. The model of ‘lean’ for instance has been adapted by the NHS, having first been developed by car manufacturer Toyota, in order to improve work processes, efficiency and quality through the elimination of waste and variability ([356, 357]). The process, itself a derivative from the US Department of War, has echoes of Taylorism and scientific management in addition to mechanical organisation, whereby the aim is to increase efficiency through standardisation [358]. The model of lean has been applied to healthcare systems since the late 1980s, including NHS hospital trusts, to NHS services and care pathways, including use by NHS Improvement ([359, 360]). Continued relevance of this discipline can be seen in the similarity between diagrams of the Toyota Production System, of two pillars set on top of a base and supporting a roof share and the current end-of-life ‘house of care’ model.

Whilst the term has pejorative undertones, I use it in the context of Etzioni’s research.
Wilensky [362] suggests that professionalization can be summarised as a five step process: 1) work becomes a full-time occupation 2) training schools established – eventually associated with university education but not necessary initially 3) professional association formed (often coupled with a name change) 4) legal protection of job role secured 5) code of ethics established (p.142-5).
Appendix 2  

Scoping review

Search strategy used for scoping review of Embase

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<th>Location</th>
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<th>Search terms</th>
<th>Results</th>
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<td>Embase</td>
<td>25/02/14</td>
<td>(&quot;place of death&quot; OR &quot;place of care&quot;) AND (pref* OR wish* OR choice OR decision*).ti,ab [Limit to: Publication Year 2000-2014]</td>
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</tr>
</tbody>
</table>

The search was also carried out for papers published between 1999 and March 2014 in:

- Medline
- PsycINFO
- CINAHL
- British Nursing Index
- AMED
- ASSIA
- Scopus
- ISI Web of Knowledge
- Health Management Information Consortium
Appendix 3

Graph stratifying review sample by source

Preference for place of death by data source

- A
- B

Legend:
- Home - Interviews
- Home - PPC
- Home - Patient records
- Home - Survey
- Other
- No preference/Don't mind
- Unsure/depends
- Unwilling to express preference
- Missing

Data sources and years:
- Various studies from different years, comparing preferences for place of death from interviews, patient records, surveys, and other sources.

Values presented as percentage ranges from 0% to 100% for each data source.
### Table of included review papers

<table>
<thead>
<tr>
<th>Study</th>
<th>Report type</th>
<th>Study description</th>
<th>Setting/Recruitment sites</th>
<th>Disease focus</th>
<th>Population</th>
<th>Data source</th>
<th>Date</th>
<th>Key findings as reported in text</th>
<th>WOE A</th>
<th>WOE B</th>
<th>WOE C</th>
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<tr>
<td>Ahlquist, and Newton (2008) [398]</td>
<td>Poster</td>
<td>Evaluation of impact of Preferred place of care (PPC) documents. Patients cared for within South Essex Cancer Network with PPC documents</td>
<td>South Essex Cancer network</td>
<td>(Assume) Cancer</td>
<td>Patients</td>
<td>PPC document</td>
<td>Oct 2005 - Sept 2007</td>
<td>Total participants n=182. 60% preferred home</td>
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<td>Akintade, Lisk et al. 2012. [399]</td>
<td>Poster</td>
<td>Advance care planning (ACP) project in nursing homes.</td>
<td>Nursing home</td>
<td>Patients and next of kin</td>
<td>ACP form</td>
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<td>Total participants n=25, completed forms of n = 21. 100% Nursing home</td>
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<td>Arnold, Finucane, et al. (2013). [60]</td>
<td>Research paper</td>
<td>Assess preferred place of death (ppd) for patients referred to a specialist palliative care service, including why PPD is not recorded and</td>
<td>Marie Curie Hospice Edinburgh</td>
<td>94% patients had cancer</td>
<td>Patients and for a few next of kin/carers</td>
<td>Patient records</td>
<td>2009-2010</td>
<td>Total participants n=1127. 60% hospice, 37% home, 2% care home, 1% hospital, (23% didn’t have PPD recorded because; 31% concern hadn’t known patient long enough, 21% undecided or place</td>
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237
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<td>Dementia</td>
<td>family caregivers</td>
<td>semi-structured interviews</td>
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<td>Research paper</td>
<td>Patient group needs assessment. A review of Royal Brompton Hospital and King's College</td>
<td>Royal Brompton Hospital and King's College</td>
<td>Idiopathic fibrotic interstitia</td>
<td>Patients</td>
<td>Case notes</td>
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<td>Motor Neurone Disease</td>
<td>Family carers and health care professionals</td>
<td>In-depth Interviews</td>
<td>May 2010-April 2012</td>
<td>hospital (n=1), 87% Not documented (n=39). Of PPC 11% Home (n=5), 4% hospice (n=2), 2% hospital (n=1), 82% not documented (n=37)</td>
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<td>Audit of PPC document use</td>
<td>Farleigh hospice, Chelmsford</td>
<td>Chronic Obstructive Patients</td>
<td>PPC document</td>
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<td>Audit of practice to discuss and record preferences. Random sample of deceased</td>
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<td>Case notes</td>
<td>Jan 05 - Dec 06</td>
<td>documented preference n=32, of total participants n=65. GP Practice (10/19):</td>
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<td>Study</td>
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<td>Disease focus</td>
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<td>Key findings as reported in text</td>
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<td></td>
<td></td>
<td>patients from regional cancer network.</td>
<td>community matron service, nursing home</td>
<td>recorded diagnosis (n=5).</td>
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<td>80% Home (n=8), 10% hospice (n=1), 10% care home (n=1). Heart Failure Community Matrons (3/15): 67% home (n=2), 33% care home (n=1). Hospital palliative care service (11/15): home (n=7), 64% hospital (n=2 18%), 9% care home (n=1) 9% patient preferred home, carer hospital (n=1). 13% Nursing Care Home (8/16): hospital (n=1), 88% care home (n=7). In total (32/65): 53% home (n=17), 9% hospital (n=3), 3% hospice (n=1), 31% care home (n=10), 3% patient home, carer hospital (n=1).</td>
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<td>Daley and Sinclair 2006. [402]</td>
<td>Letter to Editor</td>
<td>Study of concordance. Review of records of deceased patients receiving specialist palliative care services.</td>
<td>Bradford and Airedale, West Yorkshire.</td>
<td>Not stated</td>
<td>Patients</td>
<td>shared patient electronic record system</td>
<td>Oct 2003 - Sept 2005</td>
<td>1072 patients of whom 243 had PPD recorded. 59% Home (n=144), 27% Hospice (n=65), 8% Hospital (n=20), Nursing or residential home 6% (n=14)</td>
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<tr>
<td>Department of Health (2012) [42] AND Office for National Statistics (2012) [43]</td>
<td>Report</td>
<td>National survey of bereaved people evaluating end of life services.</td>
<td>England</td>
<td>none</td>
<td>Bereaved informal carers (4-11 months post bereavement)</td>
<td>VOICES survey</td>
<td>Autumn 2011</td>
<td>Total participants answering question n=19,888. 71% Home, 3% Hospital, 5% Care Home 7% Hospice 14% somewhere else (52%, Patients hadn't expressed a preference 5% Unsure if had a preference)</td>
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<tr>
<td>Dorman and Kirkham 2010. [403]</td>
<td>Poster</td>
<td>Audit of practice in recording patient preferences and concordance of deceased specialist palliative care patients.</td>
<td>Dorset network specialist palliative care group.</td>
<td>Not stated</td>
<td>Patients</td>
<td>PPC document</td>
<td>Dec 2008 - Feb 2009</td>
<td>Total participants n =470. 62% documented PPC. 36% home, 11% specialist palliative care (SPC) unit or hospice, 3% either home or SPC unit, 4% care home, 4% hospital, 2% combination of the above, 2% other, 38% unknown.</td>
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<tr>
<td>Dying Matters [404]</td>
<td>Website</td>
<td>Study of public attitudes and preferences.</td>
<td>England, Scotland and Wales</td>
<td>None</td>
<td>Population</td>
<td>Interview survey</td>
<td>July-Sept 2009</td>
<td>Total participants n= 1,375. 70% home</td>
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<tr>
<td>Evans, Finucane et al. 2014 [48]</td>
<td>Research paper</td>
<td>Retrospective case note review of patients who died under the care of a specialist palliative care service to establish whether there</td>
<td>Marie Curie Hospice Edinburgh</td>
<td>Patients</td>
<td>Case notes</td>
<td>6 month period in 2012</td>
<td>Total participants n=299 Patients whose preferences were recorded once n=95: 35% Home, 24% Hospice, 5% Care Home, 1% Relatives, 35% Unknown</td>
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<td>Fisher and Duke 2010.</td>
<td>Research paper</td>
<td>Audit of referrals patients referred for to hospital discharge team for end of life care (EOLC) discharge.</td>
<td>Southampton hospital</td>
<td>Cancer and non-cancer</td>
<td>Patients</td>
<td>medical records or asked patients</td>
<td>May-July 2009</td>
<td>Participants whose preference was recorded twice n=204. First recorded preference: Home (n=39), Hospice (n=31), Care Home (n=1), Relatives (n=0), Unknown (n=133) Second recorded preference: Home (n=68), Hospice (n=82), Care Home (n=1), Relatives (n=1), Unknown (n=52)</td>
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<tr>
<td>Frame, Ring, et al. 2012. [406]</td>
<td>Poster</td>
<td>Baseline audit of current practice in hospital of advance care planning, EOLC pathways and achievement of PPC and PPD. Retrospective case note audit of 163 consecutive adult deaths.</td>
<td>3 London acute hospitals</td>
<td>All. 33% cancer</td>
<td>Patients</td>
<td>Case notes</td>
<td>2010</td>
<td>Total participants n=163 patients. PPC: 52% Hospital (n=13), 28% home (n=7). PPD 44% Hospital (n=11), 12% Home (n=3)</td>
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<tr>
<td>Gandy, 2010. [53]</td>
<td>Research paper</td>
<td>Economic analysis of the cost of providing care to dementia patients.</td>
<td>Four care homes Greater Manchester.</td>
<td>Dementia</td>
<td>Patients</td>
<td>Deceased patient records</td>
<td>Oct 2006-Set 2007</td>
<td>Total participants n=30. 60% home (n =18), 27% hospital (n=8), 13% no preference recorded (n=4).</td>
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<td>Gerrard, Campbell, et al. 2011. [44]</td>
<td>Research paper</td>
<td>Audit of congruence of deceased patients referred to hospital palliative care team.</td>
<td>St George's Healthcare NHS Trust, London</td>
<td>Between 2/3rd (2007) and 3/4 (2009) patients</td>
<td>Patient or carer</td>
<td>Case note review and in 2009 also 'specific internal'</td>
<td>Jan -June 2007, April -Sept 2009</td>
<td>2007: Total participants n=236 of which n=149 patients had recorded preference. 44% Home (n=66), 36% hospice (n=52),</td>
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|       |             |                   |                           | had cancer    | documentation.  | 9% hospital (n=14), 11% nursing home (n=17). Total number of preferences 149/236.  
2009: Total participants n=275 of which n=166 patients had recorded preference.  
24% Home (n=39), 38% hospice (n=63), 31% hospital (n=52), 7% nursing home (n=12). Total preferences 166/275.  
49 patients refused to discuss PPC. |

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<th>Study</th>
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<tr>
<td>Gomes, Higginson, et al. 2012. [41] AND Gomes, Calanzani, et al. 2011.[40]</td>
<td>Report AND Research paper</td>
<td>European study of patient preferences for place of death.</td>
<td>All regions in England.</td>
<td>None</td>
<td>Population</td>
<td>Telephone survey</td>
<td>May - Dec 2010</td>
<td>1351 randomly selected adults. Own home 63% (n=829), home of a relative or friend (n=15)1.1%, hospice or palliative care unit 29% (n=381), hospital - but not palliative care unit 3.2% (n=42), care home 2% (n=26), Elsewhere 1.7% (n=23)</td>
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<tr>
<td>Grande and Ewing 2008 [407]</td>
<td>Letter to Editor</td>
<td>Study of patient and carer preferences for death at home.</td>
<td>3 hospice at home services</td>
<td>not stated</td>
<td>Patient and carer (Patient responses only reported in Table 2).</td>
<td>Patient records</td>
<td>4 month period</td>
<td>Total patient and carer preferences n= 255. 79% Home (n=201), 15% hospice (n=39).</td>
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<tr>
<td>Grande and Ewing 2009. [408]</td>
<td>Research paper</td>
<td>Study of impact on congruence on carers' bereavement outcomes of deceased patients using</td>
<td>5 hospice at home services</td>
<td>Cancer and non-cancer</td>
<td>Patient and carer (Patient responses only reported in Table 2).</td>
<td>Electronic data record</td>
<td>4 month period</td>
<td>Total participants n= 216, patients recorded preferences n=172. 84% Home (n=145), 12% hospice (n=21). 97 carers expressed preferences (45% of</td>
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<tr>
<td>Hall 2007 [409]</td>
<td>Research paper</td>
<td>Review of audit tools completed by nurses to assess patient need and measure congruence.</td>
<td>Easington, Co. Durham.</td>
<td>90/108 had cancer, rest had variety of conditions</td>
<td>Patients</td>
<td>Nurse-completed audit tool</td>
<td>Autumn 2005-Spring 2006</td>
<td>Total participants n=108. Home (n=89), hospice (n=5), care home (n=9), hospital (n=2), Unknown (n=3)</td>
<td>1</td>
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<tr>
<td>Hickey and Quinn 2012 [410]</td>
<td>Research paper</td>
<td>Awareness-raising campaign in South West Essex about end of life care planning.</td>
<td>Two main town centres in South West Essex.</td>
<td>Population</td>
<td>Survey at public awareness roadshow</td>
<td>March 2010</td>
<td>Total participants n=304. 63% home, 21% hospice, 6% hospital, 2% nursing home, 0.5% residential home, 17% unable to decide, 4% other. 1% didn't respond.</td>
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<tr>
<td>Higginson, Hall et al., 2010a [38] AND Higginson, Hall, et al., 2010b [39]</td>
<td>Poster AND Letter to Editor</td>
<td>Study to examine changes in relatives’ preferences for place of death.</td>
<td>Palliative care service of a London Hospital</td>
<td>Cancer</td>
<td>Bereaved relatives</td>
<td>Interviews (n=8) or postal questionnaire (n=10)</td>
<td>Total participants n=18. Home (n=7), hospice (n=5)</td>
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<tr>
<td>Holdsworth and Fisher 2010 [29]</td>
<td>Research paper</td>
<td>Explore recording rate of preferences and the congruence between preferred and actual place of death.</td>
<td>3 hospices in South East England</td>
<td>Majority of patients had cancer</td>
<td>Patients</td>
<td>Hospice records</td>
<td>6 month period</td>
<td>Total participants n=298. 27% Home (n=80), 10% hospice (n=29), 1% hospital (n=2), 1% care home (n=4), 3% Other (n=9), 2% no preference (n=7), 56% missing (n=167).</td>
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<tr>
<td>Hunt and Addington-Hall 2012 [411]</td>
<td>Oral presentation abstract</td>
<td>To explore end of life care preferences and determine predictors of</td>
<td>Two health districts in UK</td>
<td>All</td>
<td>Bereaved relatives</td>
<td>Self-completion post-bereavement survey</td>
<td>April 2010 - 2011</td>
<td>Total participant n=473. 68% home.</td>
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<tr>
<td>Hunt, Shlomo et al. 2014a [412]</td>
<td>Research paper</td>
<td>Explore reported preferences for place of death and experiences of care in a population based sample of deaths from all causes.</td>
<td>Two health districts in England</td>
<td>None</td>
<td>Bereaved informal carers</td>
<td>VOICES Short Form Survey</td>
<td>October 2009-2010</td>
<td>Total participants n=1142. “Did he or she ever say where they would like to die?” 36% Yes (n=412) 64% No (n=741) Where did he say he would like to die? 74% Home (n=296), 11% hospice (n=43), 5% hospital (n=21), 7% care home (n=25), 3% somewhere else (n=13), 1% Changed mind (n=3).</td>
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<tr>
<td>Hunt, Shlomo et al. 2014b [45]</td>
<td>Research paper</td>
<td>To explore experiences of EOLC among the oldest old and determine their reported preferences for place of death. Compared oldest old (over 85 year old) preferences with under 85 year olds.</td>
<td>Two English health districts</td>
<td>All (cancer 15.8%)</td>
<td>Bereaved relatives</td>
<td>self-completion post-bereavement survey</td>
<td>April 2010 - 2011</td>
<td>Total participants n=473. Over 85 weighted n=657.6: 82.2% Home, 4.6% Hospital, 8.3% Care Home, 2.3% Hospice, 1.4% changed mind, 1.2% Somewhere else. Under 85 years old weighted n = 714.1: 67.5% Home, 5.2% Hospital, 5.3% Care Home, 16.5% Hospice, 0.8% Changed mind, 4.8% Somewhere else.</td>
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<tr>
<td>Ingleton, Morgan, et al., 2004 [413]</td>
<td>Research paper</td>
<td>Study of satisfaction with end of life care service in the last year of life.</td>
<td>Powys, Wales</td>
<td>Cancer</td>
<td>Informal carers</td>
<td>Modified VOICES survey</td>
<td>1999-2001</td>
<td>Total participants n=301. “Did they say where they wanted to die?” 50% No (n=151), 3% Don’t know (n=10), 3% NA/Missing/other (n=8). “If yes, where was that place?”</td>
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<tr>
<td>Ipsos MORI (2010) [414]</td>
<td>Report</td>
<td>Survey of East of England designed to raise awareness in the population and inform service planning.</td>
<td>Population</td>
<td>None</td>
<td>Population</td>
<td>Survey</td>
<td>March - July 2010</td>
<td>Total participants n=693. 55% Home, 2% care home (either residential or nursing), 3% hospital, 11% hospice, 4% somewhere else, 6% don't mind, 17% it depends</td>
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<tr>
<td>Johnson and Sherwen (2010) [67]</td>
<td>Research paper</td>
<td>Evaluation of the use of Preferred Priorities for Care documents on place of death by</td>
<td>NHS West Essex</td>
<td>83% cancer</td>
<td>Patients</td>
<td>PPC document</td>
<td>July 2008 - Oct 2009</td>
<td>Total participants n=100. 1% Hospital, Hospice 17%, Home 82%.</td>
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<td>Study</td>
<td>Report type</td>
<td>Study description</td>
<td>Setting/Recruitment sites</td>
<td>Disease focus</td>
<td>Population</td>
<td>Data source</td>
<td>Date</td>
<td>Key findings as reported in text</td>
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<tr>
<td>Johnson, Nunn et al., 2012.</td>
<td>Research paper</td>
<td>Needs assessment and evaluation of service for heart failure patients served by two teams. Prospective data gathered by heart failure nurse specialists of deceased patients.</td>
<td>Bradford/Airedale and Scarborough</td>
<td>Heart failure</td>
<td>Patients</td>
<td>Data collection sheet</td>
<td>Jan-Dec 2009 (Bradford/Airedale) April - March 2010 (Scarborough)</td>
<td>Total participants n=126. Home (n=69), hospice (n=12), hospital (n=4). Approximately as read from bar chart</td>
<td>1</td>
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<tr>
<td>King, Mackenzie et al. 2000</td>
<td>Research paper</td>
<td>Evaluation of a hospice rapid-response service. Sample drawn from patients referred.</td>
<td>Highland Hospice, Scottish Highlands</td>
<td>Patients</td>
<td>Hospital, hospice local statistical records, interviews</td>
<td>April 1998-March 1999</td>
<td>Total participants n=17 All expressed wish to die at home</td>
<td>2</td>
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<td>Study</td>
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<td>Study description</td>
<td>Setting/Recruitment sites</td>
<td>Disease focus</td>
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<td>Data source</td>
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<td>Key findings as reported in text</td>
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<tr>
<td>Koekkoek, Dirven et al. 2014 [415]</td>
<td>Research paper</td>
<td>European comparative study of end of life care processes for high-grade glioma patients, focused on The Netherlands, Austria and the UK.</td>
<td>Western General Hospital, Edinburgh</td>
<td>High-grade glioma</td>
<td>Bereaved relatives</td>
<td>Questionnaire</td>
<td>2012</td>
<td>Total participants n=52 69% Home (n=36), 2% Hospice (n=1), 0 Hospital, 0 Nursing/care home, 14% No preference (n=7), 15% Other (n=8)</td>
<td>2</td>
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<tr>
<td>Koffman and Higginson 2004 [416]</td>
<td>Research paper</td>
<td>Study to explore the preference for place of death of black Caribbean population living in the United Kingdom</td>
<td>3 inner-London Boroughs</td>
<td>68% cancer</td>
<td>Next-of-kin/friend</td>
<td>Interviews with carers</td>
<td>13 months</td>
<td>Total participants n=100 Caribbean descent n=50 85% Home (n=17), 5% hospice (n=1), 10%</td>
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<td>Study</td>
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<td>Disease focus</td>
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<td>Data source</td>
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<td>Key findings as reported in text</td>
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<tr>
<td>Kingdom as compared to native-born patients with advanced disease.</td>
<td>Report</td>
<td>YouGov panel representative of all GB adults, designed to measure public attitudes towards death and dying.</td>
<td>Online</td>
<td>All</td>
<td>Population</td>
<td>Survey</td>
<td>Sept 2010</td>
<td>Total participants n=2127. 66% home 1% care home 7% hospital, 7% hospice.</td>
<td>2</td>
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<tr>
<td>Leadbeater and Garber 2010 [417]</td>
<td>Research</td>
<td>Exploring factors about place of care with terminally ill patients. N=8</td>
<td>West Highland, Scotland</td>
<td>Cancer</td>
<td>Terminally ill patients</td>
<td>semi-structured interviews</td>
<td></td>
<td>Total participants n=8. Hospital (n=4), Home (n=2), No overwhelming preference (n=2).</td>
<td>2</td>
<td>3</td>
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<tr>
<td>McKeown, Agar et al. 2008 [55]</td>
<td>Research</td>
<td>Retrospective audit to assess referral practices for patients with End-Stage Renal</td>
<td>Royal Liverpool University Hospital palliative care team</td>
<td>End-stage renal failure</td>
<td>Patients</td>
<td>Case notes then audit form</td>
<td>March - April 2006</td>
<td>Total participants n=29. PPC documented in n=14. 50% Home (n=7), 29% hospice (n=4), 14%</td>
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<td>Study</td>
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<tr>
<td>Newton, Clark et al. 2009 [418]</td>
<td>Research paper</td>
<td>Evaluation of the introduction of an advanced care plan into community and inpatient settings.</td>
<td>Acute and community settings across South Essex.</td>
<td>majority cancer patients</td>
<td>Patients</td>
<td>adjusted PPC document,</td>
<td>Oct 05-Sept 07</td>
<td>Total participants=182. 64% home, 7% hospital, 25% hospice, 4% care home</td>
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<td>Key findings as reported in text</td>
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<tr>
<td>Norfolk Health Overview and Scrutiny Committee (2005) [419]</td>
<td>NHS Report</td>
<td>Review of palliative care services including a consultation of the general public on</td>
<td>Norfolk County and Waveney District</td>
<td>Population</td>
<td>Population</td>
<td>Self-completion survey</td>
<td>Total participants n=524: 74% own home, 10% hospice, 6% don't know, 5% main hospital, 4%, elsewhere, 3% nursing</td>
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<td>Study</td>
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<td>Key findings as reported in text</td>
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<td>attitudes, experiences and expectations of end of life care.</td>
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<tr>
<td>Office for National Statistics (2013)[420]</td>
<td>Report</td>
<td>National survey of bereaved people evaluating end of life services.</td>
<td>England</td>
<td>none</td>
<td>Bereaved informal carers (4-11 months post bereavement)</td>
<td>VOICES survey</td>
<td>15 week period.</td>
<td>Total survey respondents n=22,635. For question on preferences for place of death n=21,973. 81% Home, 8% hospice, 2% hospital, 7% care home, 2% somewhere else.</td>
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<tr>
<td>Oxenham, Finucane et al. 2013[46]</td>
<td>Research paper</td>
<td>Hospice PPD audit and re-audit 7 years later following changes to practice to improve identification,</td>
<td>Marie Curie Hospice Edinburgh</td>
<td>Patients</td>
<td>Patient records</td>
<td>2005-2006 (first audit) and 2012-2013 (second audit)</td>
<td>2005-2006 (n=164): 60% home, 37% hospice, 2% nursing home, 1% hospital. 2012-2013 (n=196): 52% home, 43% hospice, 5% other locations.</td>
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<td>Study</td>
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<td>Data source</td>
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<td>Key findings as reported in text</td>
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<tr>
<td>Peacock, Riches et al. 2011[421]</td>
<td>Poster</td>
<td>Audit of completion of patient advanced care plans.</td>
<td>Royal Derby Hospital, Derby</td>
<td>Colorectal cancer</td>
<td>Patients</td>
<td>‘Gold Record’ care plan</td>
<td>May 2009 – Jan 2010</td>
<td>Total participants n=45. 67% home (n=30), 5% care home (n=11), 18% hospice (n=8), 4% hospital (n=2)</td>
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<tr>
<td>Pearse, Saxby et al. 2005[422]</td>
<td>Letter to Editor</td>
<td>Looking at why patients often did not achieve preferred place of death. Considered 100 consecutive terminally ill patients referred to palliative care team.</td>
<td>Leeds Teaching Hospital Palliative Care Team</td>
<td>90% cancer patients</td>
<td>Patients</td>
<td>Patients were asked their PPD</td>
<td>Total participants n = 100. 51% home, 29% hospice, 17% hospital, 3% unsure</td>
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<td>Shucksmith, Carlebach et al. 2013[423]</td>
<td>Report</td>
<td>2012 British Social attitudes survey, a representative national survey</td>
<td>National survey</td>
<td>none</td>
<td>Public</td>
<td>National survey</td>
<td>June-Nov 2012</td>
<td>Total participants n=3248. 67% home, 7% hospital, 4% hospice,</td>
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<td>Study</td>
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<td>4% somewhere else, 14% 'do not mind'</td>
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<tr>
<td>Sives, Cornbleet et al. 2008 [424]</td>
<td>Poster</td>
<td>Audit of proportion of patients referred to a UK hospice specialist community team who have their PPC documented.</td>
<td>Hospice</td>
<td>Patients</td>
<td>Case note review</td>
<td>July 2006 - June 2007</td>
<td>Total participants n=583 with PPD data available for 28% (n=162). 78% home.</td>
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<td>Swindlehurst, Walton et al. 2006[425]</td>
<td>NHS Report</td>
<td>Audit of practice adherence to Gold Standards Framework (GSF) register.</td>
<td>GP practices in Shropshire County and Telford and Wrekin PCT.</td>
<td>Mainly cancer</td>
<td>Patient records</td>
<td>April-Sept 2005</td>
<td>Total participants n=20. Home (n=144), hospice (n=34), community hospital (n=9), acute hospital (n=9), other (n=5).</td>
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<tr>
<td>Thomas, Morris et al. 2004.[32]</td>
<td>Research paper</td>
<td>Qualitative study to explore terminally ill Morecambe Bay. Patients referred to</td>
<td>Cancer</td>
<td>Patients</td>
<td>Interviews with patients</td>
<td>2000-2002</td>
<td>Total participants n=41.</td>
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<td>Study</td>
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<td>Thompson-Hill, Hookey et al. 2009[426]</td>
<td>Research paper</td>
<td>Audit of ‘the supportive care plan’ to assess documentation of preferred place of care and patient and family understanding of patients’ illness.</td>
<td>Researchers by palliative care professionals</td>
<td>Acute hospital</td>
<td>Patients</td>
<td>Supportive Care Plan (similar to PPC)</td>
<td>From April 2008</td>
<td>24% Home (n=10), 20% Hospice (n=8), 22% Home or hospice (n=9), Hospital 0, 3% Other (n=1), 24% Not decided (n=10), 7% No preference (n=3).</td>
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<tr>
<td>Waghorn, Young et al. 2011[50]</td>
<td>Research paper</td>
<td>To explore the relative importance of place of death to cancer in-patients and out-patients.</td>
<td>Royal Marsden Hospital</td>
<td>Cancer</td>
<td>Patients</td>
<td>Questionnaire</td>
<td>Total participants n=120. Home (n=51), nursing home (n=2), hospice (n=39), oncology centre (n=12), other hospital (n=2), unsure (n=13), no answer (n=1)</td>
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<td>Walker, Read et al. 2011[427]</td>
<td>Research paper</td>
<td>Audit of use of PPC tool and documentation of conversations relating to preferred place of death using a random sample of notes.</td>
<td>Midlands hospice</td>
<td>Patients</td>
<td>Case notes</td>
<td>Jan 2008, Jan 2009, Jan 2010</td>
<td>Total participants n=150. 79% Home, 21% hospice.</td>
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<td>Weir, Magowan et al. 2011 [428]</td>
<td>Poster</td>
<td>Audit of palliative care given to patients to inform service development.</td>
<td>Altnagelvin Hospital, Derry</td>
<td>Lung cancer</td>
<td>Asked during final admission</td>
<td>2010</td>
<td>Total participant n =26, of which n=14 stated PPD. Home (n=10).</td>
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<tr>
<td>Wood and Salter 2013[27]</td>
<td>Research paper</td>
<td>Report on end of life priorities, focusing on preferences for place of death. Includes a public survey on outcomes participants</td>
<td>UK</td>
<td>None</td>
<td>Public survey</td>
<td>Total participant n = 2,038. 63% home, 28% hospice, 8% hospital, 1% care home</td>
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<tr>
<td>Wood, Storey et al. 2007 [429]</td>
<td>Letter to Editor</td>
<td>Retrospective analysis of first 100 completed and returned assessments of patients’ end of life care preferences using preferred place of care tool.</td>
<td>North west England, two NHS primary care trusts</td>
<td>Patients</td>
<td>PPC document</td>
<td>Feb 03 -Feb 05</td>
<td>Total participants n=100. 73% home, 12% home or hospice, 9% hospice, 2% community hospital, 1% hospital, 1% home or community hospital, 1% home patient/hospice family, 1% home or hospital or hospice</td>
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Appendix 5

Interview schedules

ACE Study healthcare professionals interview schedule

Thanks, study information, confidentiality, anonymity, don’t have to answer questions, audio recorder etc. Sign consent / confirm verbal consent

Background

1. Tell me a little bit about you and how you came to be involved in [name] care?
2. What was your role?

Admission

3. Can you talk me through what happened?
4. Why do think these events [insert key ones] happened?
5. Did you want [name] to be admitted to hospital? Why? Why not?
6. Did you expect them to come home from hospital or not?
7. Do you recall there being anything that at the time you would have liked to have been different about the decisions made or the care [name] received?

Wishes/Preferences

8. Did you know what [name] wanted – did they want to die in hospital?
9. Had you discussed it with them?
10. Overview/Retrospective judgment
11. Looking back now, what do you feel about the admission (and/or your feelings on the decisions made and the chain of events)?
12. What kind of factors (E.g. psychological, clinical, social- family/patient responses) influenced the decision?

Appropriate/avoidable admission

13. From your point of view, do you feel that the admission was appropriate?
14. Thinking back, do you think there were things that could have done to avoid this admission?
15. From your point of view, do think the admission was avoidable?

Policy

16. Policy views many admissions where people die within 3 days as undesirable. What’s your view of this?
17. Policymakers would like fewer people to die in hospital and more to die at home. What’s your view of this?

Thanks. Vouchers. Expenses form if appropriate
Understanding Hospital Admissions Close to the End of Life (ACE) Study

ACE STUDY NEXT OF KIN/MAIN CARERS INTERVIEW SCHEDULE

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<th>Thanks, study information, confidentiality, anonymity, don’t have to answer questions, audio recorder etc. Sign consent.</th>
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**About you**

Could we start with a few questions about you?

1. What do/did you do?
2. How would you describe your health?
3. Which GP are you registered with?
4. Can I confirm what your relationships were with [name of deceased]?
5. Could you tell me a bit about how you were involved with their care?

**About [name]**

The main focus of our conversation is about [name] and their final admission to hospital.

6. Could you start with telling me about their recent health before their final admission?
7. Can you talk me through what happened around that last admission?
   a. Who did what and when?
   b. How was that for you?
   c. How were you involved? (Call ambulance / GP, take patient to hospital, etc.)
   d. Do you remember how you felt about [patient] going into hospital?
   e. Do you know how [name] felt/what [name] thought about going to hospital at the time?
   f. Did you expect them to come home from hospital or not?
   g. Do you recall there being anything you would have liked to have been done differently at the time?
   h. Looking back now, how do you feel about the decisions made and chain of events?
   b. Did you know at the time where [name] would have preferred to die?
      a. Had you discussed it with them?
8. Some people say it is better if fewer people die in hospital and more at home. Do you have any thoughts on this based on your experience?
9. Is there anything else that you would like to mention?

| Thanks. Vouchers. Expenses form if appropriate. Check OK and give Bereavement Support Sheet. Follow-up call in two days – best time, number, OK/NOT to leave message. |
CONSENT FORM (CLINICIAN AND FORMAL CARERS INTERVIEWS)

Please initial each box to indicate agreement with the following statements:

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<td>1.</td>
<td>I confirm that I have read and understand the information sheet dated ___ version ___ for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily. I understand that I am free to request further information at any stage.</td>
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<td>2.</td>
<td>I understand that my taking part is voluntary and that I am free to decline to answer any questions or to withdraw at any time, without giving any reason, and without disadvantage.</td>
</tr>
<tr>
<td>3.</td>
<td>I agree to the interview being audio recorded and understand that what I say may be used anonymously as part of the final report and journal articles.</td>
</tr>
<tr>
<td>4.</td>
<td>I have read and understood the above, and give consent to take part in the research study.</td>
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</table>

Name of participant __________________________ Date __________________________ Signature __________________________

Name of researcher __________________________ Date __________________________ Signature __________________________

**Further information and contact details**
The ACE research team is Dr Stephen Barclay, Dr Aileen Walsh and Miss Sarah Hoare.
If you would like more information or have any questions, either now or in the future, please feel free to contact one of us at:
Institute of Public Health, Robinson Way, Cambridge CB2 0SR.
Tel: 01223 746558 Mobile: 07795580422 Email: ACEstudy@medschl.cam.ac.uk
CONSENT FORM (NEXT OF KIN/MAIN CARER INTERVIEWS)

Please initial each box to indicate agreement with the following statements:

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Name of researcher: __________________________ Date: __________________________ Signature: __________________________

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