

# **Access to hospice care and socioeconomic position: a multiple case study**

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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## Abstract

**Background:** There have long been concerns that some people who could benefit from hospice care do not access it, including those living in socioeconomically disadvantaged circumstances. There is uncertainty about the extent of socioeconomic inequities in accessing hospice care in UK settings, and little evidence about the factors influencing access.

**Aim:** This study examines how socioeconomic position is related to access to hospice care in the UK. It aims to explore the association between hospice referrals and area social deprivation, and the factors influencing how healthcare professionals generate, and respond to, hospice referrals in the context of social deprivation.

**Methods:** Taking a multiple case study approach, this study includes analysis of data from hospice referral records and interviews with healthcare professionals caring for people at the end of life. Generalised linear modelling and thematic analysis are used to explore access to hospice care in three different cases, each located in North West England, before comparing findings in a cross-case analysis.

**Findings:** The relationship between social deprivation and access to hospice care in each case was underpinned by how hospices adapted to the local organisational and population context. Social deprivation was not statistically significantly associated with hospice referral rates, but healthcare professionals described challenges and tensions when supporting some patients in the most socially deprived areas. Good working relationships with hospitals may have facilitated hospice referrals of patients from the most socially deprived areas.

**Conclusion:** Hospice care in the UK can be organised in ways that facilitate referrals of patients from the most socially deprived areas. This study encourages an understanding of equitable access that goes beyond referrals to consider how access to hospice and other end-of-life care is continuously generated through interactions between healthcare professionals and patients.

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# Chapter 1. Introduction

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## 1.1. The 2020 context to this thesis

The way that people die exposes the inequalities in the way that people live. This was never clearer than in 2020, the year when much of the world was temporarily shut down by the global COVID-19 pandemic. In the UK, the government's initial description of the virus as the 'the great leveller', undiscriminating in who it infects, was robustly challenged as it became clear that some groups of people were more at risk than others (Milne, 2020). The gaps entrenched in society for decades became increasingly impossible to ignore as COVID-19 had a disproportional impact on the most vulnerable in society - those with unstable employment, chronic health conditions, the elderly, or living in overcrowded accommodation, unsafe home environments, or in care homes (Mueller et al., 2020, Oliver, 2020, Patel et al., 2020). Although the UK and the rest of the world could scarcely claim to be ignorant of the relationship between the social and economic circumstances of people's lives and their health, the pandemic made it impossible to ignore.

The bulk of the work that went into this PhD was completed before the COVID-19 pandemic began, although the thesis was mostly written while living under restrictions imposed as result of the virus. The subject at hand was in some ways relevant and yet wholly distant from what was happening in the UK at that time. As I wrestled with describing the way that hospices understood and responded to those dying in less than ideal circumstance, providers were overhauling their services to adapt to sudden and significant changes in end-of-life care and bereavement. While reflecting on the contribution of pre-COVID healthcare research to post-COVID healthcare delivery, the topic of this thesis still felt pertinent. The question of how hospice care is provided to those who are socioeconomically disadvantaged is still important to ask as healthcare providers fall back to their old roles in a new world. Now, more than ever, it is useful to know how hospices can work towards providing equitable access to their services. As the post-COVID era invites new ways of organising health and social care there is arguably no better time to think about how to structure services so they accommodate the needs of all patients.

## 1.2. The problem to address

Facilitating access to healthcare is not the only way to make dying more equitable but it is, for many, a gateway to achieving better deaths. Hospice care has a fundamental role in the UK in shaping how people die, and the quality of life they experience in the time leading up to their death. As a cornerstone to palliative and end-of-life care in the UK, access to hospice care should not be a luxury but a right for all those who need it (Clark et al., 2005). Despite this, there has long been concern that some people who could benefit from hospice care do not receive it, including those who are socioeconomically disadvantaged.

The term socioeconomic disadvantage is used in this thesis to distinguish those who are in a more disadvantaged socioeconomic position relative to others in society. While social stratification is relevant across different disciplines, socioeconomic position is a term often associated with health research, particularly epidemiology (Galobardes et al., 2007). Indicators of individual socioeconomic position include but are not limited to income, education, and employment, through which individuals obtain skills, knowledge and assets (Lynch and Kaplan, 2000). While measures of socioeconomic position used in this way focus on individuals, or population groups, these indicators derive from social structures. Consequently, socioeconomic position cannot be divorced from the wider society in which people live, and is both the product of how society is structured and how individuals act within the constraints of society (Graham, 2007).

Socioeconomic position has long been associated with health outcomes, with those in a more disadvantaged socioeconomic position nearly always experiencing poorer health (Lynch and Kaplan, 2000, Marmot et al., 2020, DHSS, 1980). While accessing healthcare alone is not sufficient for overcoming these differences, access to healthcare is considered a vital component to an equitable healthcare system, facilitating opportunities to improve health outcomes (Oliver and Mossialos, 2004). Any differences in access to hospice care between socioeconomic groups should be a concern to all those interested in fairness and equity at the end of life. In the UK, uncertainty about the extent of differences in access to hospice care between socioeconomic groups, and scant evidence about the factors influencing this access, means hospices and other end-of-life care providers have little guidance to help them understand and respond to potential socioeconomic inequities in this area. The hope is that this

thesis will encourage reflection within the hospice and end-of-life care profession and point towards some practical approaches to try to improve access to hospice care for those who are socioeconomically disadvantaged.

### **1.2.1. Research question**

How is socioeconomic position related to accessing hospice care in UK settings?

### **1.2.2. Aims**

- (1) Explore the association between area social deprivation and referrals to hospice care, and the influence that provider and population characteristics have on this.
- (2) Explore the factors influencing how healthcare professionals generate, and respond to, hospice referrals in the context of social deprivation.

## **1.3. Hospice care: a UK perspective**

Hospice care is a central component to this study. Closely affiliated with the philosophy of palliative care, hospice care involves a holistic approach to caring for people with advanced illnesses, and their families, attending to a person's physical, emotional, social, and spiritual needs (Clark, 2007). In the UK, hospice care is provided by specialist health and social care professionals via a range of different services, the availability and nature of which varies between organisations (Payne et al., 2017). Most of this care is provided in a person's home, but other key services include outpatient care, inpatient care, and day hospice (Hospice UK, 2017a). In this way, hospice care in the UK differs to that in the United States, where it is predominantly associated with community-based care and can only be provided to patients who are no longer receiving curative treatments (National Hospice and Palliative Care Organization, 2020, O'Connor, 2007).

While, in the UK, any person requiring palliative care could in theory be referred to hospice care, most patients who receive a referral have a cancer diagnosis and are usually within the last few months of life

(Allsop et al., 2018, Hospice UK, 2016). Although most hospices are charitable organisations that sit outside the NHS, they often work closely with health and social care professionals within the NHS, supporting and supplementing other palliative and end-of-life care (Payne et al, 2017). Hospice care in the UK is, then, largely specialist end-of-life care provided in conjunction with other NHS care, with hospices playing a fundamental role in shaping death and dying in the UK.

#### 1.4. The structure of this thesis

This thesis begins by describing the background to the research and some of the key terms and concepts to the topic such as hospice referrals and social deprivation (Chapter 2). It then moves on to describe the theoretical model (Chapter 3) that features throughout and provides a structure to the systematic review of literature in Chapter 4. In identifying gaps in the evidence specific to the UK, the systematic review is a springboard for the rest of the thesis, with findings from the review contributing to decisions about the methodology guiding primary data collection and analysis. A detailed description of the multiple case study methodology, and the mixed methods included within, are described in Chapter 5.

Chapters 6-7 present the results of the study. The two results chapters in this thesis correspond to the key phases of a multiple case study: the within-case analysis (Chapter 6) and the cross-case analysis (Chapter 7). In Chapter 6, the results of a statistical and qualitative thematic analysis are presented separately for three different ‘cases’, each one exploring access to hospice care in a specific geographic area. The intent is to provide an overview of the cases and highlight some of the relevant characteristics specific to each case. The key findings of the study are those presented in Chapter 7. This chapter outlines the results of a cross-case analysis, exploring the commonalities and differences between the cases in how socioeconomic position (specifically social deprivation) is related to access to hospice care. These findings, and their implications for practice and further research, are discussed in light of existing literature in the discussion chapter (Chapter 8) before ending the thesis with a short concluding chapter (Chapter 9). Appended to this thesis are detailed results from the statistical analyses conducted in each case. While sufficient information for understanding and interpreting the within and cross-case results are included in the main thesis, these appendices provide further clarification and detail where necessary.

## Chapter 2. Background

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### 2.1. Introduction

Hospice care and the socioeconomic stratification of society are two significant features of contemporary UK life that both have a role to play in determining how people die. Reflections on death and dying in the UK have long considered the importance of social and material conditions alongside formal healthcare services in influencing experiences of dying (Clark, 2014). There is value in considering the relationship between socioeconomic position and access to hospice care, with socioeconomic inequities in access considered unfair and morally problematic. Introducing these ideas, this chapter begins by defining hospice care and describing how hospice referrals facilitate access to this care. Social deprivation is presented as a measure of socioeconomic position, alongside some background on the historical use of these terms in healthcare research. The final section bridges these concepts together, summarising existing literature on the relationship between socioeconomic position and access to hospice care.

### 2.2. Hospice care

Many people dying from an advanced illness may benefit from, and receive, a referral into hospice care. While not everyone with an advanced illness will need hospice care, it can improve people's experiences at the end of life as they navigate the challenges associated with dying from their conditions (Candy et al., 2011). Estimates from data collected in 2016 suggest that 212,000 people received hospice care that year, approximately 32% of all people who died from conditions that could potentially have benefited from palliative and end-of-life care input (Hospice UK, 2016). While some people may receive palliative care from providers other than hospices, there is feasibly a considerable population who could benefit from hospice care but who do not receive it. Understanding who receives hospice care, and who does not, is important information for all those concerned with fairness and equity in death and dying.

Hospice care in the UK today grew from the modern hospice movement pioneered in 1960s Britain by social worker, nurse, and doctor Dame Cicely Saunders. Initially developed to help patients with terminal cancer diagnoses to die pain free, the hospice movement is closely associated with palliative and end-of-life care (Seymour, 2012). Saunderson's holistic approach to care, one that acknowledges emotional, spiritual and social distress as well as physical pain, remains central to palliative and end-of-life care today. A holistic approach is fundamental to formal definitions of palliative care, with the World Health Organisation (WHO) describing it as improving:

quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2002, p.84)

While the WHO definition is commonly adopted, there is considerable debate about how best to define and distinguish palliative and end-of-life care, and by extension hospice care. Changes to definitions can reflect wider shifts in how death, dying, and need for care are understood. A recent example is the repositioning of palliative care around serious health-related suffering, with a consensus panel arguing for a “shift from a disease-centred conceptualization to a more person-centred approach to [palliative care] (sic)” (Radbruch et al., 2020, p.760). Others have sought to widen inclusion with the term end-of-life care, which does not have the same attachment to the care of patients with cancer as the term palliative care (Seymour, 2012). While arguably less tied to cancer, end-of-life care tends to focus on the last year of a person’s life (Seymour, 2012), potentially excluding those patients who could benefit from earlier palliative care input.

This study draws on contemporary descriptions of palliative care, end-of-life care, and hospice care used by UK organisations involved in this area of healthcare (Box 1). They evoke the importance of protecting and enhancing quality of life but are broad and inclusive of non-medical approaches, referencing care, treatment, and support (Marie Curie, 2018) rather than the assessment and treatment of pain (WHO, 2002). In them, palliative care has the broadest remit and is applicable to those with a life-limiting illness but who may expect to live for some time. Palliative care includes end-of-life care, which is care provided to people with an advanced illness and who are probably in the last year of life, although in many cases

care is provided in the last weeks and months of life. Hospice care in the UK can be involved in providing both palliative and end-of-life care, although most hospice care in the UK is provided in the last few months of life (Allsop et al., 2018).

#### Box 1: Definitions

**Palliative care** is treatment, care and support for people with a life-limiting illness that can't be cured, and their family and friends. It helps people have a good quality of life and can be provided at any stage of an illness (Marie Curie, 2018).

**End-of-life care** is an important part of palliative care that involves treatment, care and support to help people live as comfortably as possible in the last year of life. This may be in the last year of life, or only in the last few days and weeks, when people may need more support (Marie Curie, 2018).

**Hospice care** aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. (Hospice UK, 2020b)

Hospice care has evolved from the early days of inpatient beds in a small number of voluntary hospices into a much broader model of care. Over half of the care (57%) provided by hospices in the UK is delivered in people's homes or place of residence, followed by outpatient care (17%), inpatient care (16%), and day hospice (10%) (Hospice UK, 2017a). In addition to clinical care, hospices also typically have a public facing role. Nearly 90% of the 200 hospices in the UK are charitable organisations that sit outside the NHS, financing their services largely through voluntary donations supplemented by some statutory funding (Hospice UK, 2016). Needing to maintain a public profile, many hospice organisations run fundraising and marketing departments alongside clinical care. Sitting within the charity sector but working closely alongside NHS services, this structure may contribute to confusion among the public as to what hospice care is and who pays for it. A survey carried out by Hospice UK in 2017 found that only 57% of people knew that hospice care was free and less than half were aware that hospice care is available in community settings and not just in a hospice building (Hospice UK, 2017a).

This brief overview has introduced hospice care as holistic care that can improve the experiences of patients with an advanced illness, and their families. While associated with care in an inpatient unit, most hospice care in the UK is provided in people's homes and in the last few weeks of life. They play a fundamental role in the care of those with advanced illness and the strength of the UK's hospice movement is one of the factors contributing to the country being rated the best in the world for the quality of death and dying (Economist Intelligence Unit, 2015). While positive, this makes it imperative that

access to hospice care in the UK is equitable across society, ensuring everyone who needs it can access it.

### **2.2.1. Referrals to hospice care**

Formal definitions of a healthcare referral are hard to come by, perhaps because the purpose of referrals may differ between disciplines within healthcare. The General Medical Council (GMC), the independent regulator of doctors in the UK, defines a referral as when another practitioner is sought to provide a service that falls outside of the referrer's professional competence (GMC, 2013). This process inevitably involves the identification of a patient who would benefit from further care and attention from a different healthcare provider (Dixon-Woods et al., 2006). Many referrals in the NHS indicate a movement of a patient from primary care to specialist care, with a focus often on GP referrals, although referrals may also take place within and from secondary care, and from healthcare to non-medical services (Davies et al., 2011, Bowles et al., 2003, Bickerdike et al., 2017). They are fundamental to how people obtain healthcare appropriate to their needs but can be influenced by factors beyond a patient's clinical need, including the relationships between healthcare providers and uncertainty about the role of different services (Walshe, 2006, Dixon-Woods et al., 2006, Chew-Graham et al., 2007).

Before being referred to hospice care, patients are likely to have been under the care of other healthcare providers, perhaps for a considerable time. For many patients in the last year of life in the UK, a large amount of care received in that time will likely be from NHS healthcare professionals, such as GPs, district nurses, or specialist consultants and nurses. This care may include generalist palliative or end-of-life care, which is palliative care provided by professionals whose work is not exclusively concerned with that area (Higginson et al., 2007). However, there is little quantitative data on who receives generalist palliative care in the UK, making it difficult to be certain about how many people receive or do not receive this type of care (Dixon et al., 2015). Whether a patient is receiving generalist palliative care or not, an NHS professional may seek a referral to specialist palliative or end-of-life care when a patient's needs become more complex, for a variety of patient or organisation-related reasons (Carduff et al., 2018). Patients may be referred to an NHS provider of specialist palliative care, including community-based palliative care clinical nurse specialists within the NHS (Howell et al., 2014), or to a hospice.

While sitting outside the NHS, hospices usually work closely with NHS colleagues to deliver care to those with advanced illnesses. There are varying degrees of integration between providers, although most hospices tend to supplement (rather than supplant) generalist care with specialist palliative or end-of-life care (Payne et al., 2017). In practice, NHS healthcare professionals often remain involved in patient care after a referral to hospice care has taken place. While closer integration between inter-disciplinary teams is often beneficial for patients, the boundaries between generalist and specialist palliative care – and the providers of this care – can be blurred, making it hard to distinguish roles (Gardiner et al., 2012).

Given the difficulties in distinguishing the boundaries to care, it can be challenging to determine when and why to trigger a hospice referral. Later in this chapter, I outline some of the factors that influence these decisions. As becomes evident, referrals are not only driven by a patient's symptomatic needs but also by the wider organisational and societal context in which access to care at the end of life is sought. Before exploring this, I briefly introduce the understanding of 'access' in this thesis, and distinguish between referral to hospice care and access to hospice care.

### **2.2.2. Referrals and access to hospice care**

This study is concerned with access to hospice care, with a focus on hospice referrals. Referrals are an important component of accessing care but referral and access are not interchangeable terms. Access is understood in this study as a dynamic and continuous process of negotiation, taking place over multiple interactions between healthcare professionals and patients within a specific organisational and social context (Dixon-Woods et al., 2006). This may include a referral to other services. Studying referrals is, therefore, helpful for understanding access but the term 'referral' itself is not synonymous with 'access', which encompasses a much broader experience and process. This study focuses on hospice referrals as a component to access, acknowledging that the factors influencing referral may occur long before actual discussions about referrals take place. This could include earlier interactions people have with healthcare, or societal norms around death and dying. Access to hospice care also continues after referral, for example in the quality of ongoing care. The interest in access to hospice care throughout this study focuses on hospice referrals but is inclusive of other healthcare interactions that take place in the last year of life. These concepts and how they relate are explored in greater detail in Chapter 3.

### **2.2.3. Factors influencing referrals**

Although hospice care is predominantly specialist end-of-life care, the boundaries between end-of-life care and palliative care, and between specialist and generalist care, can be blurred. There are likely to be some common factors influencing both access to hospice care and access to other palliative and end-of-life care providers. Acknowledging this, the following overview of factors influencing hospice referrals includes evidence relating to other providers of palliative and end-of-life care. In describing general barriers and facilitators to accessing this care, this section provides a foundation for the later discussion of socioeconomic position and access to hospice care.

#### **2.2.3.1. Need for hospice care**

Assessing need for hospice care is fundamental to generating hospice referrals as it, in principle, helps referrers separate patients whom need generalist support from those who need specialist palliative or end-of-life care. What constitutes need for specialist palliative or end-of-life care is not, however, easy to define. Ideally, need should be assessed in relation to the holistic care associated with specialist palliative care, considering a range of different patient characteristics, such as physical or emotional symptoms, spiritual distress, preferences, and prognosis (Hui et al., 2016). Emphasising the key principles underpinning a holistic palliative care approach, this conveys what should be assessed when assessing need for palliative care, but not what is assessed in practice.

Other approaches consider how need is assessed in real life. Complexity, or complex needs, is an alternative term used to describe the needs of patients who might benefit from more intensive or specialist palliative care (Tuca et al., 2018). Complexity frameworks, used in the context of healthcare need, recognise that biological determinants combine with social, environmental, cultural, and other factors to influence understanding and assessment of healthcare needs (Safford et al., 2007). Studies that approach need for palliative and end-of-life care through the lens of complexity reveal the importance of professional skills and confidence (Carduff et al, 2018) as well as system and societal factors (Pask et al., 2018) in generating complexity and consequently greater need for care. This challenges the more idealist view that need for palliative care referral should be determined by individual patient symptoms;

in practice, need for specialist palliative care is likely driven by the interaction of many social and organisational factors beyond those relating directly to an individual patient.

Need for palliative care is also defined at a population level, offering a population health approach to palliative care in addition to the focus on individual clinical care. Estimating population need for palliative care is necessary for health service planning and resource allocation, with concerns about potentially growing numbers of people who will need palliative care calling for better estimates of population need (Etkind et al., 2017). Population need may include the prevalence of symptoms within a population, perhaps in conjunction with the availability and effectiveness of services (Higginson et al, 2007). In practice, measures of population need are often limited in scope, usually relying on mortality as a proxy indicator of symptom burden (Rosenwax et al., 2005, Murtagh et al., 2013, Etkind et al., 2017). While acknowledging their limits, proxy indicators of population need for palliative care are a necessary component to any study of referrals across different populations.

#### 2.2.3.2. Decisions to refer

In addition to need, many other factors relating to healthcare professionals, patients, and society can influence hospice referrals. The following section provides a brief summary of some of these factors, considering the barriers that all patients may face when accessing hospice and other types of specialist palliative or end-of-life care.

##### *Healthcare professionals*

Much of the evidence on factors influencing access to specialist palliative and end-of-life care emphasises barriers healthcare professional face around making referrals, reflecting their fundamental role in transitioning patients to a service. Supporting patients to transition into palliative care requires healthcare professionals to be highly skilled communicators (Schofield et al., 2006). Difficulties communicating prognosis to patients and a general lack of training in, and understanding, of palliative care are seen as contributing to poor access (Dalgaard et al., 2014, Aldridge et al., 2015, Ahmed et al., 2004). Practical and time constraints on these conversations, as well as the emotional burden for healthcare professionals, have also been identified as challenges (Kirby et al., 2014). Others suggest that

discussions about referrals are complicated by concerns about leaving patients feeling abandoned or hopeless (Mrig and Spencer, 2018), difficulties overcoming stigma associated with palliative care terminology, and a perceived loss of professional control (Salins et al., 2020). Barriers to making hospice referrals relate, then, to challenges beyond the clinical assessment of patients.

In addition to interactions with patients, the attitudes healthcare professionals have towards each other are also important. The strength of the relationship between referrers and those providing specialist palliative care services can influence referrals, with collaborations based on trust, respect, networking, and on standardised models of care improving the integration of services (den Herder-van der Eerden et al., 2018, Firn et al., 2015, Walshe et al., 2008). The perceived appropriateness of a referral also depends on how healthcare professionals assess the skills and responsibilities of others, in relation to their own (Firn, Preston, and Walshe et al, 2016). In short, the nature of professional relationships and approaches to team working appear to influence access to this care.

#### *Patients and families*

Access to hospice care is also driven by how patients and families perceive, understand, and relate to palliative care and end-of-life care. For example, there are low levels of awareness of palliative care and misunderstanding about accessing it, with many people in the UK believing they have to pay for care (Hospice UK, 2017b, Shalev et al., 2017). Studies with patients for whom palliative care may be beneficial suggest that a referral to palliative care is associated with a diminished hope and choice (Collins et al., 2017) and is not seen as relevant to conditions that do not feel immediately life-threatening, such as heart failure (Dalgaard et al, 2013). Patients are also likely to wait for their clinician to suggest palliative care options rather than seek them out (Aldridge et al, 2015). Seen alongside clinician preferences to wait until a patient asks for their prognosis (Gott et al., 2011) or until a patient perceives their own need for palliative care, even to the point of waiting for them to experience suffering (Spencer et al., 2017), this feasibly creates a stalemate for discussions about referrals.

#### *Societal context*

Hospice referrals are also contextualised by the society in which they occur, with societal factors shaping the environment in which hospice care is discussed. Hospices in the UK are, for example, subject to the shifts and movements in national economies; their reliance on public donations means funding is dependent largely on the ability of their local community to donate money, coupled with statutory funding. Austerity measures taken by the UK government following an economic recession over the past decade led to cuts to public funding within the charity sector, which may have had a potentially greater impact on socially deprived areas (Jones et al., 2015). The economic environment has only become more difficult following the COVID-19 pandemic (Mahase, 2020). While this economic environment might appear distant from the decisions about hospice referrals, it has consequences for how far hospices can sustainably stretch their services. Prior to the pandemic, a third of hospices in the UK had already cancelled or delayed plans to introduce or expand services due to cost pressures (Hospice UK, 2019). In 2020, following COVID-19, a third said they were considering staff redundancies (Hospice UK, 2020a). These decisions are likely to have consequences for the extent and type of care that hospices provide, with a potential knock-on effect on what constitutes an appropriate hospice referral.

Attitudes towards hospice care and other clinical care at the end of life also reflect societal norms about death and dying. In their critical analysis of the conceptualisation of barriers to hospice referrals in the United States, Mrig and Spencer (2018) argue that healthcare professionals' emotional struggle to stop promoting curative care is intractable from the biomedicalisation of health and healthcare that seeks technoscientific innovations for the human body. This creates what the authors term "a political economy of hope" which appears contradicted – at least conceptually – by hospice care (Mrig and Spencer, 2018, p.111). While specific to the culture of healthcare provision in the United States, this highlights how referrals happen within a social context that may be hard for those involved to discern but nonetheless influence interactions between professionals and patients. In the UK, concern that death is a taboo has led to a national 'dying matters' campaign and efforts to engage different communities in end-of-life care (Hickey and Quinn, 2012). Along with clinical, emotional, and practical difficulties in talking about hospice, palliative, and end-of-life care, any societal discomfort with death may further complicate matters.

#### **2.2.4. Concerns about inequitable hospice referrals**

This description of hospice care in the UK, and the factors influencing access to it, highlights the complex clinical, professional, and social context to referrals. Given this, there has long been concern that some groups of people who could benefit from hospice care do not receive a referral, with some suggesting in its original conception hospice care provided a bit of heaven for the few (Clark et al., 2005) or offered “deluxe dying” to a small number of people (Douglas, 1992, p.579). Those who may face barriers to receiving a referral include people with a non-cancer diagnosis (Ahmed et al., 2004), people of colour (Dixon et al., 2015), older adults (Burt and Raine, 2006), and people with a history of homelessness (Hudson et al., 2016). Different circumstances are associated with different barriers, and people belonging to multiple disadvantaged groups may experience a multitude of challenges trying to access the care they need towards the end of life (Hanratty and Holmes, 2011).

Inequities are not the cornerstone of UK government strategy in end-of-life care but they are mentioned in several key documents. The 2008 End-of-life care Strategy from the Department of Health specifically calls on hospices to "consider how to ensure equity of access to their services for the whole of the population of the catchment area that they serve" (Department of Health, 2008, p.161), reiterated later in the government's response to a national review of choice at the end of life (Department of Health, 2016). A national partnership of organisations involved in end-of-life care in England also agreed a priority ambition for the sector is to ensure 'each person gets fair access to care', including tackling inequalities in quality care (National Palliative and End of Life Care Partnership, 2015). Other reports have also drawn attention to specific groups vulnerable to being excluded from this care (Care Quality Commission, 2016), leading to changes to how some hospices address inequities (Lawrance, 2020). Although socioeconomic inequities are not always specifically highlighted in these documents, there is willingness and drive from policy and practitioner circles to achieve equitable access to care in England and the rest of the UK.

Although committed to improving inequities in access to end-of-life care, these strategy documents rarely define what it is meant by inequities, or what are commonly described as inequalities. While recognising that equity is a term debated across disciplines, this study draws on the conceptualisation of equity developed within the fields of health and healthcare by Margaret Whitehead and Gören Dahlgren

(Whitehead and Dahlgren, 2006, Dahlgren and Whitehead, 1991): social inequities in health are defined as variations in health outcomes between different social groups that are systematic, socially produced and unfair. Inequities are systematic and socially produced because they need to be amenable to change; those outside the control of human endeavour cannot be remedied and cannot, therefore, be considered unfair (Dahlgren and Whitehead, 2006). In this definition, inequities differ from inequalities, which are differences that are not necessarily systematic, socially provided and unfair. While sometimes used interchangeable within policy literature, this study uses the term inequities, as defined above.

### 2.3. Socioeconomic position

This study examines inequities in access to hospice care by exploring the relationship between area social deprivation and access to hospice care. To understand the influence of social deprivation, however, it is necessary to understand what is meant by socioeconomic position, to which social deprivation is closely attached. Socioeconomic position carries a particular meaning, stemming from a scientific and philosophical approach that distinguishes it from terms such as socioeconomic status or social class, although these are often used interchangeably (Krieger, 2001, Graham, 2007, Galobardes et al., 2007). Contemporary uses of social deprivation measures are closely linked to ideas about socioeconomic position, insofar as social deprivation is often derived from multiple indicators of social and economic position (Ministry of Housing, Communities and Local Government, 2019a).

Approaches to measuring socioeconomic position in studies of health and healthcare typically reflect the belief that the stratification of society can be understood from the perspective of individuals and their resources (Lynch and Kaplan, 2000). This perspective grew from the work of social theorist Max Weber, who suggested the distribution of resources – skills, knowledge, and assets – within a society generate differences in socioeconomic position, resulting in varying abilities of people to benefit from that society (Galobardes et al., 2007). This understanding led to measures of individual (or sometimes household) income, education, and occupation becoming widely used as indicators of socioeconomic position, particularly within health research (Phelan et al., 2004). Through their socioeconomic position, people hold different amounts and types of resources that enable them to contribute to and gain from society to a varying degree, with subsequent effects on their health (Whitehead and Dahlgren, 2006, Phelan et al.,

2004). Expanding on this, some have argued that it is not the mere presence of resources that is important but how those resources effect people's capabilities to obtain desirable outcomes, including good health (Venkatapuram, 2011).

While socioeconomic position may be measured at an individual level (e.g. income), it cannot be divorced from the wider society in which people live and the structures of that society. The mechanisms by which social structure and individual action determine socioeconomic position and affect health have long been discussed and debated within the field of social stratification and health (Øversveen et al., 2017). While some position themselves firmly in one camp over another, others argue that socioeconomic position is both structurally determined (at a societal level) and actively produced (by individuals), with this reflecting the joint role of structure and agency in driving people's experiences and actions (Graham, 2007, Galobardes et al., 2007). The understanding of socioeconomic position underpinning this study is one that recognises socioeconomic position can be measured at an individual or area level but is generated by structural forces beyond individuals or areas.

### **2.3.1. Inequities beyond socioeconomic position**

While socioeconomic position has historically been the focus of much research and policy work on inequities in health, inequities relate to more than socioeconomic factors. An individual's – or group's – position in society corresponds to a multitude of characteristics and identities, including their gender, ethnicity, age, and where they live. The argument that experiences of (dis)empowerment and (dis)advantage relate to an individual's multiple identities – sometimes called 'intersectionality' – stems from research on gender and race (Crenshaw, 1991). This has since broadened to many other areas, with a case for an intersectionality lens to be applied to studies of inequities in health (Gkiouleka et al., 2018). In research on hospice and end-of-life-care, there is growing recognition that disadvantages in end-of-life care do not operate in a vacuum from one another and that intersectionality is relevant to experiences at the end of life (Stajduhar et al., 2019, Gott et al., 2020). Even where studies do not use an intersectional lens in their design or analysis – such as this PhD study - at the very least, the interpretation of research findings relating to socioeconomic position should acknowledge the potential for people to experience the effects of socioeconomic position differently depending on their gender, ethnicity, age, and their belonging to other potentially disadvantaged groups.

Equally, some characteristics that may interact with socioeconomic position to influence experiences and outcomes within healthcare pertain not to individual characteristics but to those of areas. In the UK, there is evidence that people in seemingly ‘similar’ socioeconomic positions experience different health outcomes depending on where they live. While people in the North of England are often more disadvantaged in their health than those in the south (Whitehead et al., 2014), such broad interpretations risk over-generalising experiences that differ between small geographical areas. For example, premature mortality is much worse in Glasgow than that in Manchester and Liverpool, even though the cities appear similar in their socioeconomic profiles (Walsh et al., 2010). Additionally, efforts to examine inequities in northern England tend to focus on cities rather than the vast rural and coastal areas that make up ‘the North’ of England. For example, the ‘Due North’ report that looked at inequities in health outcomes between the North and South of England mentions Manchester 20 times, but only refers to rural areas in the North once and makes no mention of coastal inequalities (Whitehead et al., 2014). Encouragingly, a more recent report into the ‘state of the North’ (Raikes et al., 2019), focusing on economics rather than health, does acknowledge rural and isolated areas such as the Tees Valley and Cumbria as less economically resilient, and nods towards coastal areas and areas with BAME populations experiencing worse outcomes as a result of the COVID-19 pandemic. This highlights the necessity of studying area socioeconomics in relation to other area characteristics, and understanding the local context to inequities in areas that appear similar in their socioeconomic profiles.

The approach taken in this study recognises that equitable access to hospice care, particularly referrals, is a matter of concern for different population groups but focuses largely on one characteristic: social deprivation. In the following section, I explain what is meant by social deprivation and its use as a contemporary measure of socioeconomic position in studies of social inequities in healthcare. As will become clear, experiences of living in a socially deprived area can vary between and within areas. While this study will not focus on the intersection of particular characteristics of people or areas, an understanding of social deprivation as a term encompassing multiple interacting circumstances and conditions is present throughout this thesis. This idea is briefly introduced in the following section, before the chapter ends with the worlds of socioeconomic position and hospice care brought together in an overview of relevant literature.

### 2.3.2. Social deprivation

Social deprivation is a term used to describe the overall impact of multiple social and economic characteristics, usually ascribed to a population or geographical area. Contemporary uses of social deprivation as a measure of socioeconomic position typically characterise areas as either more or less deprived in comparison to one another (Ministry of Housing, Communities and Local Government, 2019b). Consequently, the actual experience of living in the most socially deprived areas depends on the conditions of life in society at large (Townsend, 1979).

While different measures of social deprivation draw on different socioeconomic indicators, they tend to include measures of income, employment, and other assets (Townsend et al., 1988, Ministry of Housing, Communities and Local Government, 2019a, Carstairs, 1995). Some – such as the Index of Multiple Deprivation (IMD) – go beyond material deprivation to also include education, crime, access to services, and environmental hazards (Ministry of Housing, Communities, and Local Government, 2019b). Generally speaking, populations living in more socially deprived areas tend to have lower household incomes, fewer education qualifications, greater unemployment, and higher rates of crime. Greater social deprivation also both reflects (Ministry of Housing, Communities, and Local Government, 2019b) and is associated with (Foster et al., 2018) poorer health. Many socially deprived neighbourhoods also tend to be urban, placing them closer to industries and housing, although often remaining economically and socially disconnected from opportunities afforded by urban economic growth (Rae et al., 2018).

Social deprivation captures some - but by no means all - of what are broadly described as the social determinants of health. The ways in which socioeconomic circumstances influence health and healthcare are broad and expansive. These social determinants of health range from the biological traits individuals are born with to the organisation of social, economic, and political systems (Whitehead and Dahlgren, 2006). Gören Dahlgren and Margaret Whitehead (Whitehead and Dahlgren, 2006, Dahlgren and Whitehead, 1991) encapsulate this in their rainbow model of the social determinants of health, where individual traits are at the centre and the general social and economic conditions in society at the outer arch, with social networks, community networks, and living and working conditions in-between. Those working to tackle the social determinants of health may choose to focus on any number of areas, although

there has been a historic trend towards focusing on so-called ‘lifestyle’ factors of individuals or groups, seen as easier to target than the general socioeconomic conditions of society (McMahon, 2019).

Contemporary measures of social deprivation such as the Index of Multiple Deprivation (IMD) capture aspects of these social and economic determinants of health but not the whole picture. In measuring factors such as household income and average education, area social deprivation indicators tend to draw attention away from factors related to individuals to consider the broader conditions in which people live and work.

#### 2.3.2.1. Defining populations in socially deprived areas

When attempting to describe populations living in socially deprived areas it is important to acknowledge the heterogeneity within areas. Social deprivation tends to reflect aggregated and average socioeconomic position in an area, meaning not everyone living in the most socially deprived areas will, at an individual level, be socioeconomically disadvantaged. For this reason, area social deprivation is best used to measure area effects; when used as an indicator of individual socioeconomic position, there is a risk the effect associated with social deprivation will be underestimated because of the variability within areas (Galobardes et al., 2007).

There is also a risk of assuming that populations living in areas that appear similar in level of social deprivation are all the same. The nature of people’s lives in socially deprived areas will depend on characteristics other than those captured in measures of social deprivation. In the UK, the experience of living in a more socially deprived area differs between urban, coastal, and rural areas, for example (Rae et al., 2018, Milbourne, 2014, Beatty and Fothergill, 2003). Ethnicity in an area also influences the nature and impact socioeconomic factors have on the lives of people living in different neighbourhoods (Garner and Bhattacharyya, 2011).

While social deprivation is a useful way to describe and compare areas, the potential heterogeneity both within areas and between areas of a similar social deprivation calls for care to be taken when generalising findings. It also suggests that relative measures of area socioeconomics may not reveal the full picture of how socioeconomic factors influence access to hospice care. As well as an area’s position relative to

others, the specific attributes, and the type and level of resources provided by those attributes, in an area may also be important. This leads to a discussion about relative and absolute measures of social deprivation, and how they relate to this study.

### 2.3.2.2. Relative and absolute approaches

Defining a population by how the socioeconomics of one area compares to another creates ambiguity about the actual population of interest. Households are described, for example, as having a lower income, but the actual income or average income is not specified. This distinction between ‘relative’ and ‘absolute’ measures of socioeconomic disadvantage is relevant to the use of social deprivation in this study.

In his seminal work on poverty and deprivation published in 1979, sociologist Peter Townsend drew on and developed the idea of relative deprivation. Townsend (1979) was critical of attempts to define absolute poverty using thresholds such as poverty lines because they required value judgements to be made about what it means to live in poverty. He proposed that disadvantage in society should be determined in relation to living standards experienced by everyone, suggesting that relative deprivation is better able to capture poverty contextualised to a particular cultural, economic, and historic setting (Townsend, 1979).

Townsend’s work (Townsend et al., 1988, Townsend, 1979), and other work around the same time (DHSS, 1980), tended to emphasise the role of material deprivation (a lack of material resources afforded people through income, employment, house ownership etc.) in influencing outcomes. This emphasis is part of a wider approach to measuring socioeconomic position that focuses on resource differences as the means by which socioeconomic position influences health and other outcomes (Galobardes, 2007). Another view on what it means to be socioeconomically disadvantaged considers not just the resources a person has but what they can do with those resources (Marmot, 2017). This approach draws from the writing of economist and philosopher Amartya Sen (1995, 1985), who defended the role that (his interpretation of) ‘absolute’ poverty has in determining socioeconomic disadvantage. Agency was central to Sen’s arguments, in which he suggested inequalities should be understood as differences in a person’s capabilities to obtain desirable outcomes, included health (Sen, 1995). Following this argument, relative

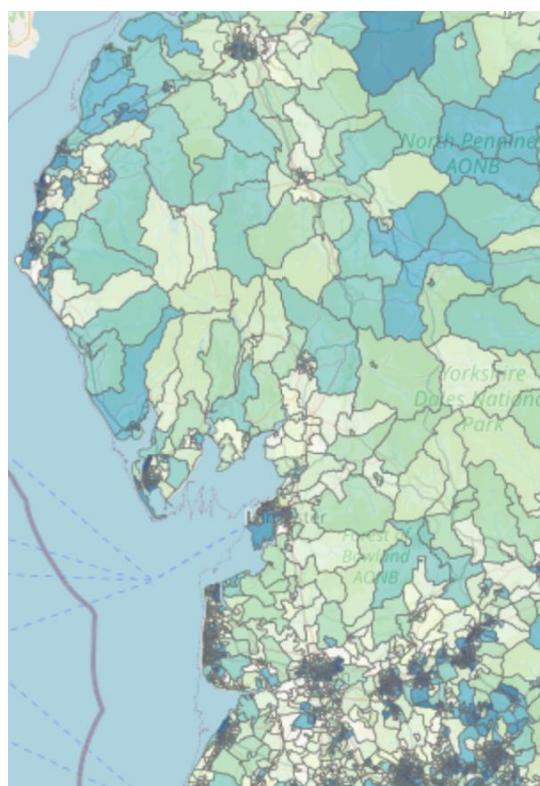
deprivation corresponds to absolute deprivation because relative deprivation results in differences in power and control to obtain the desired outcomes, implying that “it is not so much what you have that is important for health, but what you can do with what you have” (Marmot, 2015, p.2444).

When defining the population in this study, I’m interested in specifying a population in relation to both relative and absolute disadvantage; i.e. populations living in areas that are socially deprived in relation to wider society, and populations with a set of characteristics or abilities related to socioeconomic circumstances that influence hospice referrals. The assumption is that these characteristics are at least partly determined by the socioeconomic position of a population area in relation to other areas. Assuming, for arguments sake, that an area is categorised as more deprived than others partly because it is located at a greater distance from healthcare services, including a hospice’s day services, then, theoretically, residents of that area are at more of a disadvantage than those who live closer to the hospice, and the likelihood of referral may decrease with increasing distance. However, transport restrictions may mean that after a certain distance, it becomes impossible for a person to travel to attend the day hospice. The populations of interest are both those who live at a greater distance (relative disadvantage) than others, and those who live further than a specific distance (absolute disadvantage). This is a theoretical example and there is little evidence to support these assumptions about the effect of distance and transport, but the example demonstrates the *potential* relevance of both relative and absolute disadvantage.

As the rest of this chapter and subsequent two chapters demonstrate, there is limited evidence about how important different circumstances associated with socioeconomic position are for influencing hospice referrals, particularly in UK settings. Consequently, it is difficult to specify a priori which attributes of a population in a socially deprived area are of interest. This study begins by focusing on the relative deprivation of areas, and then subsequently considers how specific circumstances within the most socially deprived areas influence the ability to obtain and benefit from a hospice referral. The following section presents background information about the study setting in North West England and begins to paint a picture of some of the geographical areas of interest.

### 2.3.3. Study setting

This study takes place in North West England, the third largest region in the UK in population size and home to both some of the most and least deprived areas of the country (Young and Sly, 2010). Although a populous region, the higher population densities concentrate in the south of the region where the larger urban areas are located (Young and Sly, 2010). Most of the North-West, which roughly includes the two counties of Lancashire and Cumbria, is a mixture of rural, coastal, and small cities or towns, and it is this area, rather than the southern cities, that provides the setting for this study.



**Figure 1: Area social deprivation in North West England (2019 Index of Multiple Deprivation)**

There is considerable variation in both the extent of social deprivation in the North West and in the nature of social deprivation experienced by the people who live there. Figure 1 depicts the distribution of social deprivation measured by the 2019 Index of Multiple Deprivation (Ministry of Housing, Communities and Local Government, 2019d). The darker areas of the map indicate greater social deprivation, with the southern metropolitan areas, the Fylde coastal region (around Blackpool) and pockets of the coast further north among some of the most socially deprived areas nationally. Neighbourhoods in Blackpool account for eight of the ten most deprived nationally (Ministry of Housing, Communities and Local Government, 2019c). In contrast, large areas to the east of Blackpool and much of Cumbria appear to be at the other

end of the scale, with the pale green colours indicating areas that are some of the least deprived in the country.

While many areas in the North West are among some of the most deprived in England, the nature of deprivation within the region differs between areas. Many of the pockets of deprivation are coastal and disadvantaged in ways specific to coastal regions. Some may have a seaside tourism industry, which while bringing benefits can lead to poor quality and potentially exploitative employment because of the seasonal nature of the industry (Agarwal et al., 2018). Other coastal areas in the region, particularly around West Cumbria, have less of a seaside tourism economy and are also considerably isolated from the nearest motorway, city, and large hospital.

The economies of seaside towns are different from urban areas in the way that social deprivation manifests in those areas. Urban social deprivation in the North West tended to be tied to historical decline in manufacturing industries and subsequent effects (Dodge and Brook, 2016), whereas rural deprivation is characterised by poor access to services, fewer employment opportunities, and by general “invisibility” because of deprivation being widely dispersed (Commins, 2004). In the Index of Multiple Deprivation map in Figure 1, the rural areas – including around North Lancashire and Cumbria – appear less deprived, but this potentially masks socioeconomic diversity and inequalities within those areas.

Beyond deprivation, areas in the North West vary in other ways. While approximately 92% of people in the North West are white (Young and Sly, 2011), cities towards the south such as Preston and Blackburn have high proportions of resident minorities compared to other cities in England (Garner and Bhattacharyya, 2011). Regarding health, the north of England in general has poorer health outcomes than most southern regions, with a strong case for health inequalities being attributed to an imbalance in power and resources between regions (Whitehead et al., 2014). The North West specifically has some of the highest rates of mortality from heart disease and chronic obstructive pulmonary disease (COPD) in the country, with the highest regional mortality rates in Blackpool for COPD (Public Health England, 2020). Lancashire and Cumbria – the two counties that make up the North West – also have the highest rates of depression compared to other areas of England (Baker, 2019).

In summary, the North West is home to a wide range of populations, including some in the most and others in the least deprived areas in the country, but fairs worse than other regions in England in many health outcomes. It is in this setting that the study was conducted, focusing on exploring hospice referrals and social deprivation in three geographical areas, each one defined by the catchment of a participating hospice.

## 2.4. Socioeconomic position and referral to hospice care

There is a growing research field – explored in detail below – examining how socioeconomic position may influence access to, and receipt of, specialist palliative and end-of-life care such as that provided by hospices (Payne, 2012, Dixon et al., 2015, Davies et al., 2019). Most research comes from outside the UK, often from the United States and Canada, much of it focusing on measuring the availability, distribution, and use of services (Lewis et al., 2011, Davies et al., 2019). These studies vary in the indicator of socioeconomic position used, which is not always easily comparable to social deprivation. While different indicators may not reveal something directly about the effect of social deprivation, this wider evidence related to socioeconomic position provides a starting point for understanding the relationship between social deprivation and hospice referrals.

Note that, while this thesis focuses on access to hospice care, hospice care in the UK is closely affiliated with the philosophy of palliative and end-of-life care. Consequently, the evidence in the following section refers not just to hospice care but also to other types of palliative and end-of-life care, with the assumption that this wider literature can help reveal something about socioeconomic inequities in accessing hospice care.

### 2.4.1. Receipt of specialist palliative care and hospice services

Many studies looking at the relationship between socioeconomic position and specialist palliative care focus on use of services. A meta-analysis of findings from global literature suggests that individual socioeconomic position is associated with use of specialist palliative care services, with those in a more disadvantaged position tending to use this care less (Davies et al., 2019). This finding aligned with those of previous reviews, also of global literature and focusing on high-income countries, which suggest a

trend towards socioeconomic disadvantage being associated with fewer referrals to community specialist palliative care (Walshe et al., 2009, Grande et al., 1998).

The applicability of evidence from international reviews to UK settings is uncertain, largely because of the substantial contribution of studies from the United States. For example, the meta-analysis that found socioeconomic disadvantage to be associated with lower likelihood of using of specialist palliative care did not include any UK evidence in that section of the review (Davies et al., 2019). Although some UK studies have found evidence of socioeconomic differences in referrals to specialist palliative care (Campbell et al., 2009, Buck et al., 2018); several others found no evidence of a socioeconomic pattern to receiving specialist palliative care services (Dixon et al., 2015, Addington-Hall et al., 1998). This invites caution about applying findings from reviews of global evidence to individual countries and calls for consideration of how UK evidence may compare to that from other settings.

Caution about applying findings from US studies to the UK stems partly from the differences between healthcare and delivery of hospice care in the two countries, as well as in how socioeconomic position is understood. As with all healthcare in the US, end-of-life care operates in an insurance-based system. This generates stricter restrictions around referrals to either specialist palliative care or hospice care, seen as distinct services with separate regulations over financial reimbursement for insurers (Meier, 2011). To receive hospice care in the US, which is predominantly provided at home, patients have to be in the last six months of life and agree to forgo any further curative treatments (Meier, 2011). As charitable organisations, hospices in the UK can feasibly be more flexible in their referral criteria. Additionally, socioeconomic position in the US – and its relationship to health – is often tied to race and ethnicity, with poor data recording on other socioeconomic measures, unlike the UK's richer history of social stratification based on social class (Adler and Rehkopf, 2008). While previous global literature reviews have been rigorous and thorough, it may be inappropriate to apply findings to UK settings without better understanding of how local contextual factors relating to healthcare and social stratification influence access to specialist palliative and end-of-life care provided by hospices.

## 2.4.2. Factors influencing referral

While a large amount of evidence on socioeconomic position and access to specialist palliative or end-of-life care is about use of care, there is a growing body of work looking at the factors that might influence access. This evidence is presented here as factors relating to patients, healthcare professionals, and settings, with a focus on barriers to care.

### *Patient factors*

Issues with trust and communication between healthcare providers and patients who are socioeconomically disadvantaged may make palliative care an unacceptable option for some patients. In their review of literature on socioeconomic position and palliative care in 2011, Lewis et al. (2011) argue that experiences of accessing care by patients who are socioeconomically disadvantaged are beset with poor communication, mistrust, and stigma. Other studies have suggested that patients in the United States and Canada experiencing financial and other structural vulnerabilities at the end of life are not confident that healthcare services have their best interests at heart, believing they receive biased and differential treatment (Stajduhar et al., 2019, Adler and Rehkopf, 2008). The basis of the stigmatisation experienced by such patients may vary depending on the circumstances of their lives, including whether they have a history of drug use, homelessness, their ethnicity, or an intersection of multiple identities (Stajduhar et al., 2020, Spruyt, 1999, Hudson et al., 2016). Distrust and unacceptability of healthcare services for some patients may also be the product of personal and collective histories of discrimination, resulting in formal services being perceived as powerful authorities to be avoided (Giesbrecht et al., 2018).

As in the evidence around use of care, many examples of mistrust or distrust in the context of end of life or palliative care for patients who are socioeconomically disadvantaged are found in studies from the United States and Canada (Stajduhar et al., 2019, Lewis et al., 2011, Hughes et al., 2007, Giesbrecht et al., 2018). In the US, fear of medical bills is a persuasive deterrent against seeking healthcare for those who are on low incomes or otherwise economically disadvantaged, which is less likely to be an issue in the UK's free at the point of use system (Schapmire et al., 2012). The Canadian tiered public-private healthcare may be closer to that of the UK but still relies on medical insurance and leaves socioeconomically disadvantaged residents vulnerable to out-of-pocket expenses (Martin et al., 2018).

In both Canada and the United States, mistrust connected to socioeconomic position is also associated with wider experiences of ethnicity and race, particularly for indigenous, African-American, and Latinx populations (Williams, 2004, Nedjat-Haiem et al., 2013, Martin et al., 2018, Giesbrecht et al., 2018). While evidence from the UK is more limited, trust or mistrust in healthcare services and professionals is still relevant to the UK setting (Calnan and Rowe, 2006). In the context of end-of-life care, some UK studies have reported high levels of distrust in services among specific groups, for example among homeless populations (Hudson et al., 2016). Whether concerns about trust and acceptability disproportionately influence decisions to refer patients who are socioeconomically disadvantaged to hospice care, or can be overcome at the end of life, would benefit from further exploration.

In addition to trust, awareness and understanding of services may also influence access to healthcare at the end of life. A lack of awareness of hospice care can contribute to some patients being referred late to this type of care (Schockett et al., 2005). There is evidence that people who are more socioeconomically disadvantaged are less aware of hospice or palliative care. For example, a recent systematic review, mostly of studies surveying the wider population rather than people with an advanced illness, found consistent evidence that older white women with higher education and socioeconomic status had greater awareness than other groups of both advanced care planning and hospice care (Grant et al., 2020). While it is feasible that awareness of services would increase as people become sick, social differences in awareness can persist among patients who may benefit from palliative care. A survey of oncology patients in London, for example, found that the patients who were the most socioeconomically advantaged were more likely to recognise the term ‘palliative care’ and understand the role of specialist palliative care ‘Macmillan’ nurses than those who were disadvantaged (Koffman et al., 2007).

Other evidence points towards the importance of contextualising attitudes towards and awareness of healthcare within the wider picture of patients’ lives. Researchers who have interviewed or spent time observing people at the end of life emphasise how the effects of socioeconomic disadvantage or disempowerment can be an overwhelming part of their end of life experience (Stajduhar et al., 2019, Hughes et al., 2007). These studies highlight survival as central to patients’ experiences, as evident in the titles of the corresponding research articles: “Everyday struggling to survive” (Hughes et al., 2007); “Too busy just living in the moment and surviving” (Stajduhar et al., 2019). They convey an end-of-life experience in which it is difficult to make plans in preparation for declining health, functionality, and

ultimately death. Similar accounts, although not in the context of end-of-life care, are found among interviews with healthcare professionals caring for patients in socially deprived areas of the UK, where patients contend with a multitude of difficult life circumstances on top of managing a health condition (O'Brien et al., 2010). This evidence indicates the importance of attaching a person's attitude and behaviours towards their health and illness to the wider socioeconomic structures in which they live.

#### *Patient need for hospice care*

The evidence relating to trust and the overwhelming effects of socioeconomic circumstances suggests there is a paradox in the care of patients experiencing socioeconomic disadvantage. While these factors may constitute barriers to patients engaging with and receiving hospice care, they are also indicative of potentially greater need for care. Others have described how experiences associated with socioeconomic factors may contribute to symptoms at the end of life. Interviews with palliative care professionals suggest that income, education, social support, and belonging to a socially vulnerable group may increase symptom burden among patients, for example (Santos Salas et al., 2019). Others have pointed towards financial strain at the end of life having a greater impact on those in low income households (Hanratty et al., 2012), and there have been calls for financial pain to be recognised as part of a patient's holistic needs (Payne, 2012).

Greater symptom burden experienced by some patients who are socioeconomically disadvantaged may also impact on families. There is mixed evidence regarding socioeconomic circumstances and the role of families at the end of life. While patients in a more disadvantaged socioeconomic position may have family close by who they can draw on for support (Kessler et al., 2005), providing informal care in the context of socioeconomic disadvantage can be challenging. In an ethnographic study of family caregivers living in poverty and at risk of homelessness, Stajduhar et al. (2020) found that many of the socioeconomic issues effecting patients also effected caregivers, including concerns about finding food and stable housing. These concerns may contribute to why socioeconomically disadvantaged caregivers for patients at the end of life have also been found to experience greater levels of depression (Oechsle et al., 2019). The impact of socioeconomic factors on need for hospice care appears, then, to extend beyond the patient and into the wider family unit.

### *Healthcare professionals*

As evidenced above, there is support within healthcare policy and practice for providing equitable access to specialist palliative and end-of-life care, including that provided by hospices. However, healthcare professionals may still, perhaps subconsciously, treat patients differently because of the social and economic circumstances in which they live. Societal and biomedical narratives about people who are dependent on alcohol or drugs, for example, can neglect the complex lives and experiences of this population, leaving them misunderstood and silenced at the end of life (Witham et al., 2019). Those who, because of their substance dependency, live in unstable or insecure homes can be perceived by healthcare providers to be living in potentially unsafe or risky environments for care, leading to decisions to not put end-of-life care in place (Wales et al., 2018, Stajduhar et al., 2019). Although the evidence on the effects of bias (implicit or otherwise) on end-of-life care is small, the available research is similar to findings elsewhere suggesting that patients who are socioeconomically disadvantaged are stigmatised by healthcare professionals in clinical interactions when ill health is framed simply as a consequence of patient lifestyles, or life choices (Mackenzie et al., 2020).

Some healthcare professionals may struggle to identify need for palliative or end-of-life care related to socioeconomic circumstances because of overexposure to some of the issues at hand. Research suggests both the symptoms of serious illness, potential need for care, and even death, can be seen as just a normal part of life for populations living in difficult socioeconomic circumstances and those caring for them (Walton et al., 2018, Stajduhar et al., 2019). The normalisation of symptoms as part of daily life for patients experiencing socioeconomic disadvantage could have consequences for their access to hospice care. With hospice referrals requiring, in theory, the recognition of physical, psychological, and other complex symptoms in a patient who is entering the last few years or months of their life, there is potential that need for palliative care may go unrecognised if symptoms are presumed to be part of normal life.

### *Availability and organisation of services*

Some of the potential constraints to accessing palliative care for those who are socioeconomically disadvantaged, or living in disadvantaged areas, concern the actual availability and geographic accessibility of services (Lewis et al., 2011). One review of barriers to Medicare hospice services in the

US suggests that there may be fewer hospice inpatient facilities in more socioeconomically disadvantaged areas (O'Mahony et al., 2008). Looking at availability of inpatient hospice units in England, Gatrell and Wood (2012) identified areas where there was high deprivation and which were over 30 minutes drive from the nearest hospice, highlighting areas with potentially greater needs but poorer access. However, the authors did not test the statistical significance of that relationship. A survey of hospice at home services in England also suggested that a higher proportion operate in predominantly affluent areas than in predominantly deprived areas, although the majority cover areas of mixed deprivation (Rees-Roberts et al., 2019). There is growing evidence, then, of hospice services being potentially less accessible for people in more deprived areas of the UK.

Although studies have looked separately at different types of services, no studies appear to have explored how hospice referrals, and access more generally, vary between service types across different socioeconomic groups. Given that transport costs are a substantial burden to low-income patients at the end of life (Lewis et al., 2011), inpatient services may be less acceptable to patients whose families would struggle to travel to visit. This may explain why people living in deprived areas are less likely to die in an inpatient hospice unit (Sleeman et al., 2016). It is feasible that hospice care provided in a patient's place of residence may be more acceptable and accessible for those who are more socioeconomically disadvantaged. However, the evidence on use of hospice at home services and socioeconomic position is mixed in the UK. Whereas one study found no differences in receipt of hospice at home care by social deprivation (Dixon et al., 2015), Campbell et al. (2009) found that referrals to a hospice at home service in Manchester were higher in less deprived areas. Few studies have explored the relationship between socioeconomic position and access to specialist palliative or end-of-life care in day hospice, or in hospital settings, although use of hospitals at the end of life and dying in hospital are consistently associated with socioeconomic disadvantage (Hanratty et al., 2008b, Davies et al., 2019, Barratt et al., 2017).

## 2.5. Gaps in knowledge and understanding

While ideally hospice referrals would be triggered by patient symptoms, the inter-professional relationships, understanding and acceptability of hospice care, and social or organisational contexts are also important in influencing referral decisions. As the summary of literature above indicates, some

experiences and characteristics associated with socioeconomic position, including distrust, acceptability of care, and symptom burden and recognition, could influence referrals to hospice care (Lewis et al., 2011). Factors such as these may explain why patients who are socioeconomically disadvantaged appear less likely to receive specialist palliative or end-of-life care services (Davies et al., 2019).

Yet there is considerable uncertainty about how different factors and contextual circumstances influence hospice referrals for patients living in socioeconomically disadvantaged circumstances. Part of this uncertainty relates to how well evidence from other countries transfers to UK settings. Additional questions arise, however, from a general lack of evidence. While organisational context and working relationships between professional groups are clearly evidenced in the general literature on hospice referrals, few studies have considered how these may interact with socioeconomic factors to influence access. It is feasible, for example, that greater time pressures and fewer resources for healthcare professionals in socially deprived areas would influence their ability to form and manage effective working relationships with hospice staff, and thus influence referrals from those areas. Other unanswered questions relating to the organisation of services concern whether how and where hospice care is provided makes a difference at reaching more socioeconomically disadvantaged populations.

There is also a need to link evidence around experiences and service organisation to hospice referral as an outcome. While many studies from outside the UK have looked at the extent to which patients who are socioeconomically disadvantaged are less likely to receive hospice and other specialist palliative or end-of-life care, few have attempted to link this outcome to factors that influence use of services. There is a need for research, therefore, that explores the context to hospice referrals specific to UK settings and attempts to link this to any differences in hospice referrals by socioeconomic position. Such evidence would improve understanding about the extent to which some factors act as barriers to referrals but also potentially identify those that facilitate access. This could also help to move forward research from describing problems to identifying potential solutions from best practice examples.

While providing insight into the evidence relating to referrals to specialist palliative or end-of-life care and socioeconomic position, the evidence documented in this chapter does not provide an overarching theoretical framework that can explain how different factors influence referrals. There have been very few attempts to draw on theoretical ideas to understand this evidence holistically. An exception is Lewis

et al.'s (2011) synthesis that uses a behavioural model of access to categorise evidence relating to access to specialist palliative care and socioeconomic position. While thorough in some ways, this model fails to reflect the interactive and dynamic nature of access, which is produced through multiple encounters between patients and healthcare providers. Nor was that theoretical model designed to explain socioeconomic inequities in accessing healthcare. An alternative model of access that addresses these limitations is presented in the next chapter.

## 2.6. Summary

This study is about social deprivation and access to hospice care, with a focus on hospice referrals. Hospice care in the UK, typically accessed via a referral, is mostly provided at the very end of life but conceptually is related to the wider philosophy of palliative care. Social deprivation was presented as a contemporary measure of socioeconomic position, reflecting on the challenges of defining populations in the most socially deprived areas. The global literature indicates that worsening socioeconomic position is associated with a lower likelihood of receiving specialist palliative and end-of-life care, such as the care provided by hospices. Multiple factors relating to socioeconomic circumstances and the referrals process may influence this, including the acceptability of services, capability to engage in planned care, and how healthcare professionals recognise symptoms. However, country differences in healthcare systems, and in approaches to measuring socioeconomic positions, mean it is difficult to apply many findings to the UK setting and there are considerable gaps in understanding about how different socioeconomic factors influence hospice referrals. There is also uncertainty about the role organisational and other contextual factors have on potential socioeconomic inequities in hospice referrals. Understanding about this topic would be strengthened by more explicit inclusion of theoretical explanations for socioeconomic inequities in accessing healthcare.

# Chapter 3. Theoretical model

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## 3.1. Introduction

The previous chapter summarised how access to hospice care, specifically referrals to hospice care, may differ between socioeconomic groups. In that overview, evidence was largely categorised as relating to healthcare professionals, patients, or the wider social or organisational context. In practice, however, access is likely generated by an interaction of multiple factors (Spencer et al., 2017). Studies of decision-making in palliative and hospice care have called for more acknowledgement of the interactive nature of those decisions, which inherently involve more than one party and are dependent on organisational constraints (Spencer et al., 2017, Bélanger et al., 2011). Making a referral is an example of decision-making within hospice care generated through the interaction of multiple factors. Given this interactive dynamic, there is arguably a better way to organise and approach this topic than to delineate issues as those independently relating to healthcare professionals, patients, and systems or societies.

Efforts to present this evidence holistically – capturing the interaction between different factors – would benefit from the structure provided by a middle range theory. Middle range theory is a term that emerged from sociological research, specifically from the work of Merton (1968), to describe the structuring of abstract ideas and concepts in such a way as to permit empirical testing and study of those ideas. In guiding empirical research, middle range theories are an intermediate between general all-inclusive theories of social systems and hypotheses of constrained, narrowly defined phenomena that cannot be generalised (Merton, 1968, p. 39). Smith and Liehr (2013) describe this middle theoretical level as connecting philosophical belief systems to the worlds of practice. Such middle range theories can generate theoretical models or frameworks, described as “a structure of interrelating concepts that describe and explain the measuring of a phenomenon” (Smith and Liehr, 2013, pp. 20-21).

Building on these theoretical foundations, I have drawn in this thesis on a model that uses mid-range theoretical constructs to ground abstract ideas relating to access to healthcare within the practical ‘real-life’ interactions between healthcare professionals and patients. Dixon-Woods et al. (2006) model of

candidacy is orientated around professional-patient interactions, in which access is generated through continuous negotiations between a patient and professional over a patient's candidacy for healthcare. As detailed below, candidacy built on earlier theoretical work around access to healthcare but with a focus on those who are vulnerable to being disadvantaged both in their health and access to services. In this chapter, I introduce some of the key constructs to candidacy and consider the philosophical beliefs relevant to this theoretical model. I then explore the potential usefulness of candidacy for organising evidence related to socioeconomic position and access to hospice care.

### 3.2. Introducing the 'candidacy' model

A way of conceptualising access that incorporates the interactive and dynamic nature of accessing care is by recognising access is a process of establishing 'candidacy' for care (Dixon-Woods et al, 2006). The authors of the candidacy model describe this as a process of negotiation over a patient's eligibility for healthcare taking place over multiple interactions between patients and professionals, contextualised by operating conditions at a local level (Dixon-Woods et al, 2006). The idea that people negotiate access to healthcare through encounters with professionals is relevant to all potential patients. However, this conceptual model was developed specifically to understand how factors related to socioeconomic circumstances influence access to healthcare. The core argument is that this process of establishing candidacy leaves socioeconomically disadvantaged groups vulnerable to not receiving due care and attention. This vulnerability arises over the course of the process, including in socioeconomic patterns in how patients and professionals interact, how care needs are identified and assessed, and the conditions in which interactions take place.

Dixon-Woods et al. (2006) identified seven components – or stages – to negotiating access to healthcare. They posited that patients must *identify their candidacy* by assessing their own need for healthcare, then mobilise practical and social resources to *navigate services*. Services also vary in the ease with which they can be used. The authors conceptualise this as *permeability*. Less permeable services require greater resources to access them and demand greater cultural alignment from patients, meaning people have to be comfortable with a service provider's organisational values. Patients then make *appearances* to services and assert their claim to candidacy, a claim *adjudicated* by healthcare professionals. The sixth

stage concerns healthcare being *offered and resisted*, which may include the offer of referral to another healthcare provider and whether a patient resists offers of care or referral. The final stage recognises the local production of candidacy and that *operating conditions* create the environments in which these interactions take place. Figure 2 provides a visual depiction of these seven stages, adapted from the descriptions provided by Dixon-Woods et al. (2006).

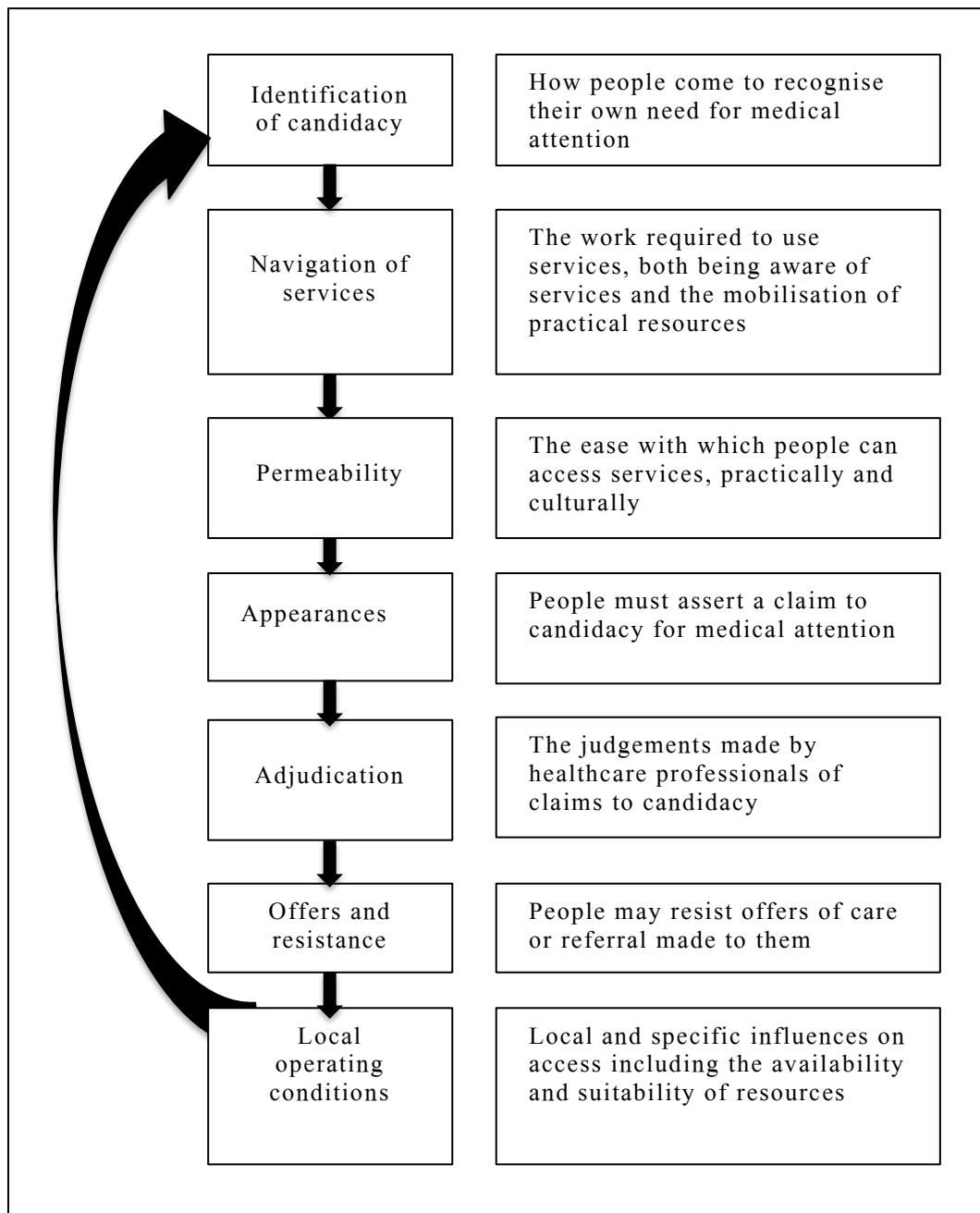


Figure 2: The 'candidacy' model (adapted from Dixon-Woods et al, 2006)

The candidacy model was developed from a synthesis of evidence about access to NHS services in the UK and socioeconomic position, funded by the Department of Health (Dixon-Woods et al., 2006). The model was then used to explore evidence relating to other vulnerable populations. This work resulted in two key publications: one long-form report (Dixon-Woods et al., 2005) and a journal article (Dixon-Woods et al., 2006).

In both publications, the authors outline how each of the seven components or stages to candidacy may be experienced differently depending on a patient's, or community's, socioeconomic characteristics. Broadly, they suggest that patients in more disadvantaged circumstances are likely to downgrade symptoms and seek healthcare in a series of crises rather than engage in planned care (Dixon-Woods et al, 2005). They also might have less knowledge of the services available and struggle to mobilise resources to attend services, or feel less comfortable doing so. During encounters with those running a service, Dixon-Woods et al. (2006) suggest there may be a social pattern in how patients use their voice to express need and demand services. Although the synthesis found only weak evidence that healthcare professionals' judgements about a patient's candidacy for a service differ between socioeconomic groups, decisions about which patients are likely to benefit may disadvantage those whose life circumstances are seen as a barrier to good health (Dixon-Woods et al, 2005). All these factors may contribute to offers of care being made, and either accepted or resisted. Finally, the authors suggest that resource scarcity or fragmented organisation of services may disproportionately effect those in more socioeconomically disadvantaged circumstances (Dixon-Woods et al., 2006). On this last point, they point out that few studies contributed to this finding, although they argue it feasibly has a considerable influence on access.

### 3.3. Building on 'access to healthcare' theory

The model proposed by Dixon-Woods et al. (2006) built upon decades of work describing how populations navigate and use healthcare services but used fresh terminology and concepts to place the patient-professional relationship at the heart of 'access'. Since the 1970s there have been many attempts to conceptualise access, offering different takes on what it means to access healthcare (Levesque et al., 2013). The most influential of these has arguably been Andersen's Behavioural Model of Access (Aday

and Andersen, 1974), which has often been employed in research studies looking at access to healthcare services (Babitsch et al., 2012). Ronald Andersen, along with colleague Lu Ann Aday, developed a complex model that recognised the influence of both patient and service characteristics on access to healthcare. In this behavioural model, influential factors are either ‘predisposing’, typically to do with patient characteristics, or ‘enabling’, tending to relate to service factors (Andersen, 1995, Aday and Andersen, 1974). Need for healthcare was included as either perceived need, on the side of the patient, evaluated need, from the perspective of healthcare professionals, or contextual need, which captured need at a population level. Access takes two fixed forms: potential access concerns the presence of enabling factors and realised access is about whether care is actually used. The aim is to understand how a combination of predisposing, enabling, and need factors either facilitates or deters realised access, usually just referred to as utilisation.

Andersen’s behavioural model brought into focus the necessity of understanding behaviours as well as service provision when trying to understand utilisation of services. Presenting a generalised model of access, in that it is designed to understand access for all populations, the model is not set up to easily capture the reasons why some groups are systematically disadvantaged in their access to care. Although some studies (Lewis et al., 2011) have applied the model to understand the relationship between socioeconomic position and access to healthcare, there is some uncertainty about the place of socioeconomic factors in the model (Blackwell et al., 2009). When discussing equity in a later iteration of the model, Andersen (1995) assigns ‘demographics’ as a predisposing factor not mutable to change, thus implying that differences at demographic levels can be considered equitable, while differences attributed to ‘social structure’ may be seen as inequitable. The distinction between social structure and demographics is unclear in this explanation; occupational class or ethnicity, for example could be measured either as a social structure or a demographic. Uncertainty about how socioeconomic factors are conceptualised in the model in relation to predisposing, enabling, or need factors, and their relation to equity, does not provide a strong foundation for a study of socioeconomic patterns to accessing hospice care.

While weak in addressing socioeconomic factors, Andersen’s work set the scene for imagining how multiple factors might interact in complex ways to generate access. This idea was picked up and emphasised by Pechansky and Thomas (1981), who talked about patients’ needs fitting into a system,

and the ability of that system to meet those needs. More recently, Levesque et al. (2013) synthesised previous conceptions of access into five dimensions of service accessibility and five dimensions relating to abilities of patients. The authors argued that these dimensions jointly feed into the process of someone having their health needs fulfilled, from the point of identifying the need to the consequence of utilising healthcare. This particular conceptual model was developed as part of a doctoral thesis (Levesque, 2006) submitted the same year as Dixon-Woods et al. (2006) published their work on candidacy. Although they do not reference each other's work, the models are similar in their recognition that access is a dynamic process rather than a static moment in time.

Where Dixon-Woods et al.'s (2006) candidacy model differs to other approaches is in how it places the relational aspect to access at the heart of the process. It is relational in the sense that access is seen as generated through interactions between people. From this starting position, the idea of negotiation surfaces; on one side a patient identifies and may seek to establish their candidacy for a service and, on the other, professionals assess a patient's eligibility as a candidate. Care can be offered by professionals and accepted or resisted by patients. Other factors – such as the types of services available and how they operate – generate the environments in which patient-professional interactions take place, limiting or expanding the terms of negotiation.

The authors of candidacy also go some way to recognise the dynamic and reiterative nature of access, recognising that previous encounters with healthcare professionals have ramifications for how patients access subsequent care. The importance of this point has been emphasised and reiterated in subsequent studies that use candidacy to explore access to a variety of services. For example, Hunter et al. (2013) describe how encounters in primary care drive subsequent decisions to seek emergency care and Mackenzie et al. (2013) also emphasise that past experiences feed into future attempts to establish candidacy. Others have identified that a relationship built on trust – which would have to be built up over time – is also critical for patients trying to express their needs and claim candidacy for care (Tarrant et al., 2015). The idea that past experiences feeds future experiences is similar to what Andersen (1995, p.7) called feedback loops, a concept he later added to his own model of access to account for the “recursive nature of a health services’ use model”.

In summary, Dixon-Woods et al.'s (2006) model of candidacy built upon earlier work recognising the dynamic nature of access but focused on using this approach to explain potential inequities in access to healthcare across socioeconomic groups. The authors place the patient-professional interaction at the heart of their model, arguing that it is through these interactions that a patient's candidacy for healthcare is decided. The stages of candidacy recognise how the actions that patients and professionals take to negotiate this access, as well as the local conditions and organisation of services, can either facilitate or prevent socioeconomically disadvantaged populations from receiving due attention and care.

### **3.3.1. Candidacy for referral**

Because this study is interested in how candidacy might relate to hospice referrals, it is necessary to clarify the relationship between referrals and access. This distinction was touched upon in the previous chapter but is developed here. In agreement with the central idea behind candidacy, I reject the idea that access itself can be measured in a binary way, where a person either accesses healthcare or does not access healthcare. Rather, access is a continuous and dynamic process of interaction. It follows from this view that there is not a single point in which access can be said to be 'achieved' or 'obtained'. Instead, access is a process by which other outcomes can be achieved, such as quality of experiences, diagnosis, treatment, or receipt of referral. All these outcomes are products of the same process of establishing candidacy described by Dixon-Woods et al. (2006).

This study is concerned with access to hospice care, with a focus on hospice referrals. If receipt of referral is an outcome of access, then the process of obtaining a referral mirrors the process of accessing care. This justifies the use of candidacy – a model of access – to identify and explain potential socioeconomic differences in hospice referrals. In the discussion above, I also acknowledged how earlier interactions patients and professionals have influence their subsequent discussions. This calls for attention on not just the immediate interactions around the referral decision but also those relating to end-of-life care more broadly, acknowledging that the nature of discussions about hospice referrals between patients and professionals are contextualised by their earlier interactions.

It is also appropriate to acknowledge that receipt of referral is not the only important outcome from the process of establishing candidacy for referral. For example, an interaction between a patient and

professional where they discuss a hospice referral may influence the patient-professional relationship and improve understanding of the condition or prognosis, or identify a patient's preferences. Conversely, such conversations may lead to a breakdown in trust or communication were a patient resistant to hospice care, or to knowing their prognosis. Equally, experiences related to hospice referrals continue after a patient has been connected with a hospice service. How hospice staff assess and respond to referrals and how patients interact with hospice care post-referral are likely to continue to influence ongoing perceptions of candidacy for care.

### **3.3.2. Philosophical underpinnings to the candidacy model**

While the idea of candidacy was developed in response to concerns about equitable access to care for different population groups, the authors of this model do not explicitly situate it within the broader literature relating to social inequities to health. Nor do they provide much detail about the beliefs and values underpinning their approach. This may be because the review from which candidacy developed served a specific policy goal and an academic methodological interest in critical literature synthesis. This arguably left the authors with little scope or motivation to state their philosophical position regarding social inequities in access to healthcare.

While not explicitly stated, it is possible to infer from this work that the authors place greater emphasis on individuals and their relationships to their immediate surroundings, than on the large social, economic, or political forces that contextualise peoples' lives. For example, in their long form report, Dixon-Woods et al. (2005) begin by referencing work by Gulliford et al. (2001) that describes access being to do with health beliefs, perceptions, and help-seeking behaviours, as well as financial, organisational, and social barriers to access. From this starting point, Dixon-Woods et al. (2005; 2006) continue to emphasise individuals and the immediate conditions in which they work and live. While they include 'local operating conditions' as one of the seven stages of establishing candidacy, their conception of these conditions tends to stay within the boundaries of health service organisation and resource allocation (Dixon-Woods et al., 2006). They do not explore the potential influence of macro political and economic contexts, and the political philosophies or ideologies therein. The absence of this has led to some describing the 'local conditions' component as the least well-developed and articulated stage of

candidacy, critiquing the theoretical model as neglecting structural influences on access (Mackenzie et al., 2013, Chase et al., 2017).

This neglect of structural influences puts candidacy somewhat at odds with wider understanding of the social determinants of health, and how they underpin social inequities in health and healthcare. For some, social inequities in health are driven by what Michael Marmot (2017), citing Geoffrey Rose et al. (2008), calls “the causes of the causes” and describes as:

...the nature of society that leads to, and tolerates, stark inequalities in conditions of daily life; and inequities in power, money and resources that give rise to these inequalities in conditions in which people are born, grow, live, work and age. (Marmot, 2017, p.539)

Marmot’s description of the causes of the causes corresponds to what Dahlgren and Whitehead (1991) describe as the outer arches of their rainbow model of the social determinants of health. These arches represent the structural influences on health, contextualising the other contributing factors. However, the candidacy model was generated from evidence more concerned with individual behaviours and social relationships. As already discussed, the inclusion of ‘local operating conditions’ in the model nods to the health service organisation section of Dahlgren and Whitehead’s rainbow but does not extend any further to consider the broader structures that determine how society functions in relation to health.

While the role of structural factors is often acknowledged in theoretical discussions about social inequities in health, it is not unusual in practice to focus on the more immediate social and economic conditions that appear to influence health and access to healthcare. Raphael (2011) identified seven discourses around the social determinants of health, ranging from healthcare services needing to be responsive to the material conditions of patients’ lives, and recognise that these conditions drive health behaviours, to acknowledging the political and economic environment to social inequities in health, and that some groups’ have an interest in creating and benefiting from inequities. A consequence of these different views on the social determinants of health is that these ideas are operationalised differently in practice, with people taking actions in light of their existing perspective on the problem (McMahon, 2019). While aware that health is socially determined, some practitioners may reinterpret this in a way that fits preconceptions of their role and remit, resulting in them focusing attention on individual

behaviours or encouraging people to make ‘better’ choices rather than on structural causes (Mead et al., 2020). The authors of candidacy are not alone, then, in arguably neglecting potential structural causes of inequities in access in favour of an approach embedded in practice-orientated clinical encounters.

Since the publication of Dixon-Woods et al.’s (2006) model, however, other research studies using candidacy have better incorporated these structural macro-level factors. In their work looking at access to care for women who died in pregnancy in Indonesia, D’Ambruoso et al. (2010) argue that these macro-level factors are critical part of the environment in which candidacy is sought. In that study, the authors use their empirical findings to turn the candidacy model on its head. Rather than access ‘beginning’ with a patient identifying a need, they suggest that the local operating conditions dictate the subsequent behaviours of professionals and patients in establishing candidacy, adding that “...the locus of control over candidacy...lies within the macro-level operating conditions” (D’Ambruoso et al, p.229). The authors contextualise poor access to obstetric care within a society that, in their view, features poor social welfare conditions, abuses of power, social conservatism, and “norms of discrimination, elitism, and a market ideology” (p.232).

Others have also argued that structural factors fundamentally impact encounters with healthcare professionals. In their study on domestic abuse disclosure in GP consultations Mackenzie et al (2019) suggest that the micro-level clinical encounters should be reinterpreted structurally, acknowledging that class, gender, ethnicity – and their relation to political and institutional practices – have an impact on how GPs and patients interact. They suggest that Metzl and Hansen’s (2014) idea of structural competency, whereby healthcare professionals are trained to recognise when clinical symptoms are the consequence of decisions, practices, and policies at a higher level, could help to address the limitation to candidacy outlined above. Such an approach, the authors argue, may help align the key component to candidacy – individual interactions between patients and professionals – with beliefs and assumptions about the importance of structural factors in determining access.

In this study, I draw largely from the model of candidacy presented when it was initially conceived (Dixon-Woods et al, 2006), whilst remaining open to how this model can be adapted for hospice care and the wider societal factors that may influence access for socioeconomically disadvantaged groups. This calls for an exploratory approach, one which considers how candidacy might be applied to this study

but is not necessarily beholden to how it is originally conceived. The following section begins this exploratory process by considering how people may become a ‘candidate’ for hospice care.

### 3.4. Becoming a ‘candidate’ for hospice care

The description of, and reflection on, candidacy above provides a starting point from which to think about the applicability and usefulness of this theoretical model to hospice care. The decision to refer patients to hospice care occurs amid multiple, potentially challenging, interactions between professionals and patients, as both parties try to understand a patient’s prognosis, needs and preferences for care. As outlined in the previous chapter, multiple interacting factors relating to patients, professionals, and the context in which care is delivered are likely to influence discussions about hospice referral and access to hospice care more generally (Ahmed et al., 2004, Aldridge et al., 2015, Spencer et al., 2017). It may be appropriate, therefore, to conceptualise access to hospice care as a process of becoming a ‘candidate’ for care, played out through multiple interactions between patients and professionals, influenced by local conditions in which care is provided and by patients’ prior experiences with healthcare.

While candidacy is a potentially useful construct for understanding access to hospice care, no studies to date have used candidacy to explore access to hospice or other types of specialist palliative or end-of-life care. An initial attempt to map evidence related to access to hospice care and socioeconomic position onto the seven stages of candidacy is presented in Table 1. The third column in Table 1 cites evidence initially presented in the background chapter, linking this to the components of candidacy outlined in columns 1 and 2.

A central argument in the work of Dixon-Woods et al (2005; 2006) is that services that require greater work on the part of healthcare professionals and patients are harder for patients who are socioeconomically disadvantaged to access. As Table 1 indicates, there is considerable work required from both healthcare professionals and patients to establish candidacy for hospice care, with some evidence suggesting this might be more difficult in the context of socioeconomic disadvantage. This difficulty is bound up with the necessity of a referral to receive hospice care, which inherently will involve some sort of referral criteria, either implicitly or explicitly. Consequently, hospice care is a

service with low “permeability” and is likely harder to access with worsening socioeconomic disadvantage.

Table 1: Stages of candidacy mapped to evidence on hospice referrals

Stage of access	Related to socioeconomic factors in original model	Evidence relating to hospice referrals
(1) Identification of candidacy	<p>Services more likely to be used as a series of crises.</p> <p>Help-seeking likely to occur in response to specific events rather than planned.</p> <p>Symptoms may be “downgraded”.</p> <p>Lack of positive conceptualising of health.</p> <p>Normalisation of symptoms due to consistent experience of ill health in self and in community/family.</p>	<p>A tendency for disadvantaged populations to focus on survival at the end of life (Hughes et al., 2007) or wait until a healthcare crisis may make it difficult to talk about involving palliative or hospice teams in their care in a planned and preparatory way.</p> <p>Symptoms indicating advanced illness may be downplayed or misunderstood by patients, although few studies have considered this in the context of palliative or end-of-life care.</p>
(2) Navigation	<p>Awareness of services on offer.</p> <p>Mobilising practical resources (e.g. time off work, financial support).</p> <p>Mobilising social resources (e.g. support at home, support for transport).</p>	<p>Differences in awareness of hospice services between socioeconomic groups (Grant et al., 2020) may lead to fewer discussions or greater misunderstandings about hospice care, and therefore rejection of referrals.</p> <p>Some people may have less access to advocates (social support) who support people to ask for help or to articulate needs.</p> <p>However, some people may have family closer by who are able to provide day to day support (Kessler et al., 2005). However, the presence and support of family may also incorrectly assume, with location of family not necessarily reflecting capacity to support.</p>
(3) Permeability of services	The way services are organised effects the ease with which people can access them (or how ‘permeable’ a service is).	Referral typically needed to access specialised hospice care, suggesting it is not very permeable.

	<p>Some services require referrals, certain symptoms, a certain diagnosis, in order to access them.</p> <p>Less permeable services ‘demand a higher degree of cultural alignment between themselves and their users’. Comfort with organisational values of service and referrer important.</p> <p>Satisfaction following previous encounters may affect later experiences.</p>	<p>Hospice care has historically been associated with care for patients with cancer and those with a non-cancer condition may continue to find it difficult to access care (Ahmed et al., 2004). The socioeconomic inequalities are greater among those dying from non-cancer conditions than cancer (ONS, 2017). This may contribute to the increasingly poor permeability of hospice care with worsening socioeconomic position.</p> <p>Experiences of stigmatisation of discrimination may lead to mistrust of services, effecting ease of access (Adler and Rehkopf, 2008, Stajduhar et al., 2019).</p> <p>A hospice death or a ‘good’ death may not be culturally aligned with the preferences of everyone in society. Hospice care may be seen as for the ‘middle classes’ (Adams, 2016).</p>
(4) Appearances	<p>People make ‘claims’ for their right to access services.</p> <p>Patients required to formulate and articulate issue in a way that aligns with clinical assessment.</p> <p>Social distance between clinician and patients may make this harder.</p>	<p>Palliative care may differ slightly in that a patient will likely already be known to a healthcare professional and will be unlikely to be ‘presenting’ for the first time with end of life symptoms. However, patients who are socioeconomically disadvantaged are more likely to be diagnosed late for some conditions (Orsini et al., 2016), which may influence discussions about, and preferences for, future care.</p> <p>Experiences of mistrust or distrust (Lewis et al., 2011) may influence how patients articulate need to referrers or hospice staff.</p>
(5) Adjudication	<p>Healthcare professionals have to make judgement calls about who to refer and who to accept into a service.</p> <p>These decisions are strongly linked to relationships with other healthcare professionals,</p>	<p>Judgements regarding hospice referrals may depend healthcare professionals’ understanding of holistic care. Whether and how financial, material, and social needs are assessed may disproportionately affect socioeconomically disadvantaged populations (Hanratty et al., 2012, Payne, 2012).</p>

	<p>local resources and capacity.</p> <p>Healthcare professionals may ask themselves how likely a patient is to benefit from an intervention (sometimes this may have social criteria).</p>	<p>In socially deprived areas, healthcare professionals may have less time (O'Brien et al., 2010) to engage with services in local area and build their knowledge of local palliative care support available. However, they may seek to build resilience through multidisciplinary team working (Eley et al., 2018), which may result in greater hospice referrals.</p> <p>Judgements about the lives of patients and their home environment may influence assessment of appropriateness for hospice care (Reimer-Kirkham et al., 2016, Wales et al., 2018, Wilson, 2009). Death, or symptoms, may be normalised (Stajduhar et al., 2019).</p>
(6) Offers and resistance	<p>Patient (or family) may resist offers of referral.</p> <p>Resistance may be due to patient's identification of candidacy (see above) or perception of service.</p>	<p>Rejection may occur because of normalisation of symptoms, mistrust, awareness of services, or a preference to focus on survival rather than dying (see sections 1-3 above).</p>
(7) Operating conditions	<p>Locally specific influences on interactions between patients and clinicians.</p> <p>Fragmented complex systems harder to navigate for disadvantaged groups.</p> <p>Resource scarcity may prevent referrals (tied to adjudication).</p>	<p>As with all healthcare services, there is a limit to number of people who can receive care from hospice. When service capacity is reduced, disadvantaged groups may be more likely to miss out due to the reasons outlined above.</p> <p>Some models of hospice care may be more acceptable than others to patients living in socially deprived areas or experiencing socioeconomic disadvantage. For example, studies of hospice at home found no evidence of a difference in use of services by social deprivation (Dixon et al., 2015), but the likelihood of dying in a hospice inpatient unit decreases with worsening social deprivation (Sleeman et al., 2016).</p>

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Hospices depend on local public donations (Hospice UK, 2016), which may result in different level of resource and capacity between affluent and deprived areas.

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An additional central component to the candidacy model is that access is jointly negotiated. Therefore, the circumstances and behaviours described for patients do not operate independently from other factors but interact with those relating to healthcare professionals to generate access. These interactions are also dependent on the permeability of services and the local conditions to access. The abstract idea of factors ‘interacting’ with one another to influence access to hospice care is realised in a more concrete way in Box 2, which describes a fictitious patient and situation where eligibility for candidacy is being negotiated. This example was not generated through observations or primary data collection but is an imagined scenario. The intent is to demonstrate the potential usefulness of candidacy for providing an overarching narrative to the phenomenon of accessing hospice care for people experiencing socioeconomic disadvantage.

**Box 2: Janet’s candidacy for hospice care**

Janet is a 58-year-old woman with advanced chronic lung disease who lives alone in a one bedroom flat in a deprived area of town. After a recent exacerbation of her illness, she becomes increasingly anxious about being able to keep the meter topped up over the coming winter. She books a GP appointment at her surgery to talk about her worsening physical symptoms. She is given a ten-minute consultation with a GP whom she has not met before. The GP suggests Janet attends a COPD support group at the hospice. However, Janet turns down the referral because she is not sure if the hospice care expects a financial donation in return. In any case, she knows the hospice is the other side of town and she cannot afford the bus to get there. She feels ashamed and does not want to tell the doctor her worries about money and the GP does not enquire or explain that there are free transport options. Because she is not considered to be at the end of life, Janet is not offered a visit from hospice at home or told about the inpatient unit. However, Janet’s illness worsens over the next six months and she dies in hospital having not had contact with a specialist palliative or end-of-life care team.

In the example above, Janet's candidacy for hospice care is influenced by factors that have an interactive effect on access. For example, she perceives a stigma associated with her economic position that contributes to her resistance to care; in turn, a healthcare professional neglects to consider Jane's financial difficulties when assessing her holistic needs. Janet's relationship with her GP surgery is heavily influenced by the capacity and organisation of healthcare services, which determines the amount of time she can spend with a GP and who she sees. The perception that some hospice care services are inappropriate for Janet also limits the referrals that her GP can offer. This example demonstrates, therefore, the potential interplay of local operating conditions, the permeability of hospice care (the ease with which care can be accessed), and the interaction between Janet and a referring healthcare professional.

### **3.4.1. Limitations in applying candidacy to hospice care**

One of the potential drawbacks to adapting the candidacy model to hospice care is that candidacy was originally derived around people seeking input from healthcare following the onset of symptoms. Reflecting this, the stages follow a chronological order that begins with a person identifying their own potential eligibility for care before seeking out input from healthcare professionals. With the case of hospice referrals, this chronological order may not be as appropriate. Often patients wait for healthcare professionals to bring up prognosis or palliative care, and do not trigger the conversation themselves (Aldridge et al., 2015). Equally, however, some healthcare professionals may prefer to wait until patients indicate they are ready to have that conversation (Gott et al., 2011, Spencer et al., 2017). This means the starting point of assessing eligibility for candidacy for hospice care is less likely to be as consistent and predictable than for other types of care.

While this discussion has presented a case for how candidacy could be used to build a narrative about socioeconomic position and access to hospice care, there is still considerable uncertainty about how this might look in practice. To reiterate arguments from the previous chapter, the empirical evidence relating to hospice care stems largely from countries outside the UK. In contrast, the theoretical model of candidacy was generated from a synthesis of studies looking at access to NHS care in the UK, meaning there is a strong case of its relevance to the UK settings. While this chapter includes an initial attempt to map the global empirical evidence to this theoretical model, a more appropriate assessment of the usefulness of candidacy to hospice care in the UK would draw from UK evidence. To date, however, no

studies have attempted systematically to map UK evidence on access to hospice care and socioeconomic position to the candidacy model. Additionally, using the candidacy model to help design studies of access to hospice care may elicit more certainty about its usefulness for explaining potential socioeconomic inequities in hospice referrals, with such studies exploring the fit between empirical evidence and theoretical explanation. Overall, the extent to which candidacy is, in practice, a useful model for explaining access to hospice care for socioeconomically disadvantaged populations warrants further empirical exploration.

The remainder of this thesis responds to this gap in knowledge, exploring the applicability of the candidacy model for understanding access to hospice care for those who are socioeconomically disadvantaged. The subsequent chapter reports findings from a systematic and comprehensive search for evidence in UK settings, using the candidacy model as a framework to explore these findings. The findings from this review help to determine how best to use this theoretical model to approach primary data collecting and analysis, described in greater detail in the methodology and methods chapter.

### 3.5. Summary

Like social deprivation and socioeconomic position, access is a concept that can be hard to define. Having considered the strengths and weaknesses of other models of access, such as Andersen's Behavioural Model of Access, I chose to adopt an understanding of access as a more relational and dynamic construct. In this definition, access is not a static moment or a threshold which patients either achieve or fail to obtain, but is generated through multiple, continuous interactions between patients and healthcare providers. While limited attention is given to the structural determinants of access in the original model of candidacy, it provides scope to develop this component (as some researchers have done) by acknowledging the conditions in which access is generated. An initial exploration of the theoretical relevance of candidacy to hospice care suggests it could be an appropriate model for understanding differences in hospice referral across socioeconomic groups. A more systematic application of the model to literature in the UK, and consideration of its use in primary data collection and analysis, is warranted.



# Chapter 4. Systematic literature review

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## 4.1. Introduction

Understanding who accesses healthcare and how different factors influence this access is fundamental to understanding people's experiences of health and illness. The arguments stated so far in this thesis make a clear case for the value of understanding the relationship between access to hospice care and socioeconomic position. As discussed in previous chapters of this thesis, hospice care in the UK involves the provision of specialist palliative and end-of-life care to patients with advanced illnesses and their families. Consequently, while not always directly concerning hospice care, evidence about the relationship between socioeconomic position and specialist palliative or end-of-life care in the UK is nonetheless relevant to understanding any differences in access to hospice care.

To date no systematic analysis of existing UK-based studies of socioeconomic position and access to specialist palliative or end-of-life care, including hospice care, has been undertaken. While a meta-analysis of global studies suggests that the likelihood of using specialist palliative care decreases with worsening socioeconomic position (Davies et al., 2019), this did not include any evidence from the UK. There is some evidence about which factors influence access to specialist palliative or end-of-life care and how they do so but this also often comes from countries where healthcare systems and the nature of socioeconomic disadvantage differ to that in the UK (Lewis et al., 2011). Importantly, this evidence lacks an organising theoretical framework, without which it is difficult to present an overarching narrative that can explain how different factors influence access to hospice care for people in different socioeconomic groups. There is a need, therefore, for a systematic analysis of UK literature on this topic that uses a theoretical framework to organise findings. In this chapter, I offer a solution to this problem by presenting findings of a systematic review of relevant studies carried out in UK settings. Adopting narrative synthesis techniques (Popay et al., 2006), I draw on the theoretical model of candidacy (Dixon-Woods et al, 2006) as a framework for organising and interpreting the findings. Focusing on the interactions between healthcare providers and patients, the candidacy model suggests that access to care is a process

of negotiation, requiring work on the part of patients and healthcare professionals that may disadvantage people in a more socioeconomically disadvantaged position (Dixon-Woods et al., 2006).

#### *Review aims*

This systematic review aims to understand which factors are important for influencing access to palliative care for socioeconomically disadvantaged groups, but in particular why and how they do this, using the candidacy model (Dixon-Woods et al, 2005) as a framework to explore this.

## **4.2. Methods**

This review took a narrative synthesis approach, describing findings using text rather than statistics to tell the story of the data from primary studies (Popay et al., 2006). Developed initially for synthesising intervention or effectiveness studies, the flexibility of narrative synthesis means it can be adapted for other types of data, including that from mixed methods research (Bélanger et al., 2011). The four stages of a narrative synthesis provided the overall structure of this review (Table 2).

**Table 2: Stage of a narrative synthesis**

Stages of narrative synthesis	This synthesis
Stage 1: Developing a theory of how the intervention works, why and for whom.	The candidacy theory of accessing healthcare (Dixon-Woods et al., 2006) provided a theoretical framework for understanding access to palliative care for SE disadvantaged groups. This theory was developed prior to conducting the synthesis to incorporate additional factors related to palliative care factors (Appendix C).
Stage 2: Developing a preliminary synthesis of findings of included studies.	Initial coding was carried out using pre-defined and open coding. Some studies were grouped by characteristics to try to identify patterns in the data.
Stage 3: Exploring relationships in the data	Text summaries and concept mapping techniques were used to link findings and find reoccurring themes. Data were explored using the seven stages of candidacy to see how well they fit the theoretical framework.
Stage 4: Assessing the robustness of the synthesis.	The use of a second reviewer in study selection and appraisal aimed to reduce bias and error, helping to ensure the robustness of the synthesis. This was aided by use of Hawker et al. (2002) critical appraisal tool, ensuring study quality was assessed systematically and comprehensively.

#### **4.2.1. Study searches**

A comprehensive search of the literature was undertaken to find relevant English language peer-reviewed articles and grey literature reports. Grey literature in this study is defined as research presented in non-academic, non-peer reviewed format, for example when featured in reports from charity organisations or government bodies. Search terms and subject headings relating to palliative care, access, and socioeconomic position were combined with AND in searches on journal databases AMED, Medline, Embase, CINAHL, SocIndex, and Academic Literature Search. Search terms were developed with reference to Cochrane guidance on finding palliative care literature (Cochrane Pain, Palliative, and Supportive Care, 2017) and Dixon-Wood et al.'s (2005; 2006) synthesis of access to NHS care referred to earlier. Search terms and MeSH headings were adapted and refined through multiple pilot searches. An example database search (MEDLINE) including all search terms can be found in Appendix A. Studies

were also searched for in the reference lists and citations of systematic reviews and included studies, and the websites of charities Hospice UK and Marie Curie and the UK's Department of Health were searched for grey literature between June-July 2018.

#### **4.2.2. Study screening**

The population of included studies were patients with an advanced progressive illness, or their families, or healthcare professionals/organisations providing their care. This population inclusion criteria were deliberately broad to capture not just those who may be considered for hospice referral, but also who may benefit from accessing other types of palliative or end-of-life care, including both generalist and specialist palliative care. Reiterating arguments made earlier on this thesis, while the focus of this study is on hospice care, evidence relating to other providers of palliative and end-of-life care is considered appropriate, given the feasibility that similar factors will effect access to all these types of services. The measure of socioeconomic position used to describe the population had to be explicitly mentioned in the title or abstract of the study. Studies that only considered social characteristics (e.g. gender, age, ethnicity, rurality) without linking these to economic characteristics (e.g. income, deprivation, occupational class) were excluded, as were studies published prior to 1990. This date was chosen because prior to that date many hospices in the UK were still in the early stages and had only just become established (Overy and Tansen, 2013). A table listing all inclusion and exclusion criteria is provided in Appendix B.

I screened the titles and abstracts of all retrieved studies against the eligibility criteria. A second reviewer screened 10% of these titles and abstracts and disagreements were resolved in further discussions about the inclusion criteria. This process was designed to improve the robustness of the synthesis by reducing the risk of bias or error in study selection. Initially, 3% of these titles and abstracts were compared; the two reviewers disagreed on whether to include about 30% of these initial studies. Most disagreements were the result of a reference to socioeconomic position or palliative care being missed in the initial reading by either the first or second reviewer, and were easily resolved. However, discussions about other issues, such as the definition of socioeconomic position, led to changes being made to the inclusion and exclusion criteria. These included excluding prisoners from the study population, for example, because of the difficulty synthesising their experiences with those outside of prison. In addition, alternative terms to hospice or palliative care, such as 'terminal care', were added to the study topic inclusion and exclusion

criteria. Following that, a further 3% of the studies were screened by the second reviewer and only 2% of these resulted in disagreements. Following further discussion, ‘satisfaction’ was added to the inclusion criteria as an access measure. The final 4% of studies were screened, resulting in less than 0.02% disagreements, all of which related to misreading of the abstracts and were easily resolved.

#### **4.2.3. Synthesising data**

##### *Developing a preliminary synthesis*

The analysis followed the stages of a narrative synthesis with both inductive and deductive approaches pulled upon in the analysis. To initially develop a preliminary synthesis (stage 2) I first coded the result sections of studies looking at *receipt of care* in Nvivo; these codes were then grouped by study characteristics to try to identify traits associated with different findings. I subsequently coded the results and discussion sections of studies looking at *experiences of access* using open coding and pre-defined codes from the candidacy framework (Dixon-Woods et al., 2006). These pre-defined codes were drawn from the seven key components of candidacy: identification of need; navigation of services; permeability; appearances; adjudication; offers and resistance; and local operating conditions.

##### *Exploring relationships in the data*

The relationships between findings were explored (stage 3) using concept maps, whereby codes and themes from qualitative and quantitative evidence are diagrammatically displayed to help establish links between them (Popay et al., 2006). Findings relating to the candidacy concepts were then summarised by text before re-reading the primary sources to identify any further data that could be coded under these summaries. The final themes were generated through rewriting text summaries to incorporate further findings and synthesise ideas together.

While these text summaries were initially written using the seven stages to candidacy as theme names, the limited amount evidence meant several of these themes could not be sufficiently populated. Instead, they were merged into a smaller number of themes, which reflected the core ideas to candidacy but not each of the seven stages to the model.

#### 4.2.4. Study quality

##### *Assessing the robustness of the synthesis*

To improve the robustness of the synthesis, two reviewers independently appraised the quality of the studies. While no studies were excluded based on quality, the overall quality of the studies was considered when interpreting and synthesising findings, meaning the strength of the conclusions drawn from the review corresponds to the quality of the evidence.

Study quality was assessed using Hawker et al.'s (2002) quality appraisal tool, which is suited to appraising studies that use quantitative or qualitative methods. It includes nine domains that assess both the methodological rigour and reporting quality of studies. Included studies were scored (1 – very poor, 2 – poor, 3 – fair, 4 – good) for each of the nine domains. Domain scores were then aggregated into an overall score for each study. These scores were not used to determine whether to include or exclude studies but rather as a crude overview of the range of quality in the evidence. All studies were appraised for quality by the first reviewer and 10% were appraised by a second reviewer. Domain scores for these 10% of studies were fairly similar from each reviewer, with no more than one point difference in each domain, resulting in no more than a four point difference in the overall study scores. The reviewers agreed that, given the subjectivity of the quality assessment, this reflected good overall agreement.

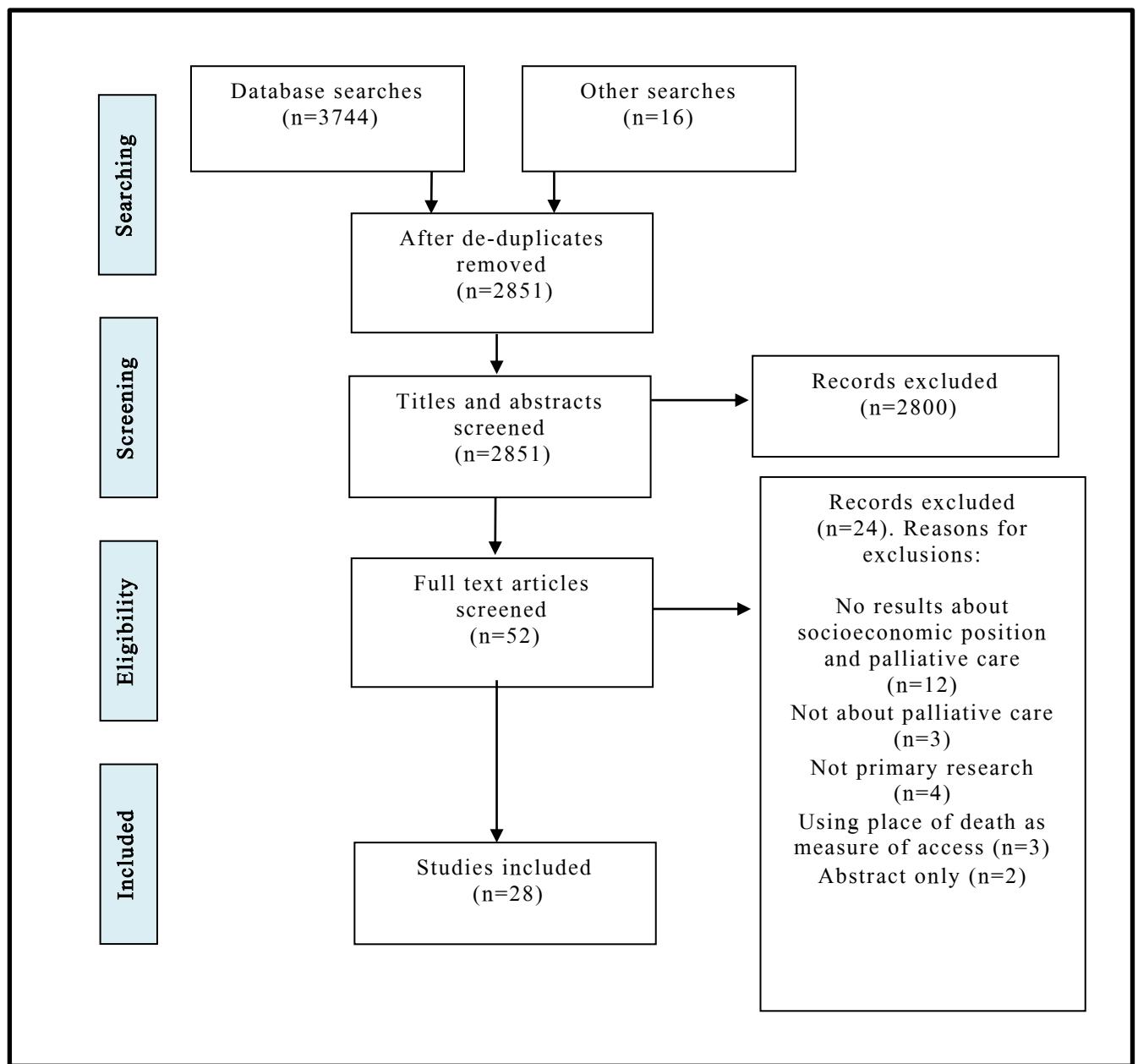


Figure 3: PRISMA flow diagram of study screening

## 4.3. Results

Searches retrieved 3760 studies, 28 of which have been included in this review. The primary studies varied considerably in purpose and in how access and socioeconomic position were measured. Area deprivation was the most common (n=12) measure of socioeconomic circumstance used within these studies, followed by social or occupational class (n=9), perhaps reflecting the historical dominance of these indicators in UK settings (Galobardes et al., 2007, Savage et al., 2013, Townsend, 1979). Over half of the studies (n=15) looked at who received care, with the rest looking at other components to access. Where studies considered different types of care (e.g. community and inpatient) or used both individual and area measures of socioeconomic position, these were considered separate findings. This meant that some studies (e.g. Grande et al., 2002; Johnson et al., 2018) contributed multiple findings to the synthesis. For example, the synthesis of findings on receipt of specialist palliative care included 16 findings from 13 studies. The characteristics of included studies are provided in Tables 3-7.

### 4.3.1. Robustness of the synthesis

The studies varied in quality, with scores ranging from 17 to 35; most scored between 25 and 30. Only one study scored below 20; a commentary piece based on non-peer reviewed primary research (Clark, 1998). However, as both reporting and methodological quality are given equal weighting in the appraisal – a limitation to the Hawker et al (2002) tool – it meant that studies could receive similar overall scores even when one was methodologically stronger than another. For example, a grey literature analysis of palliative care admissions in Wales (Marie Curie, 2014) that scored poorly on the methods and data analysis but good on the results and implications received a similar score to a peer-reviewed article that had consistently fair scores apart from issues around ethics and transferability (Kessler et al., 2005)

Many studies were not primarily interested in socioeconomic position and therefore did not interrogate it in great depth, a limitation not captured in the appraisal tool. For example, some studies only analysed socioeconomic position in a univariate analysis and not multivariate (e.g. Burt et al., 2010). This means that some findings related to socioeconomic position may be less reliable than others. Interestingly, all quantitative studies that had a primary

focus on socioeconomic position and ran a multivariate analysis (n=6) reported at least one example of socioeconomically disadvantaged groups being disadvantaged in their access to palliative care (Campbell et al., 2009, Gatrell and Wood, 2012, Hanratty et al., 2008b, Walsh and Laudicella, 2017, Wilson, 2009, Wood et al., 2004). However, these studies varied considerably in their methodologies, measures and outcomes, making it very difficult to synthesise the results of this group.

**Table 3: Studies using survey methods**  
*HCP=Healthcare professional*

Author(s)	Care setting	Aims	Population	Socioeconomic measure	Access measure	Key findings relating to review questions
<i>Specialist palliative care</i>						
Addington-Hall et al., 1998  Quality score 33	Hospice at home	Understand how cancer patients who received community specialist palliative care differ from those who did not.	Patients (proxy)	Social class (I -V)  No reference or details provided.	Receipt of care	<ul style="list-style-type: none"> <li>• Social class was not statistically significantly associated with receipt of community specialist palliative care.</li> </ul>
Addington-Hall and Altmann, 2000  Quality score 30	Inpatient hospice	Understand how cancer patients who receive inpatient care differed from those who do not.	Patients (proxy)	Social class (I-V).  Coded from occupations on death certificates.	Receipt of care	<ul style="list-style-type: none"> <li>• Social class was not statistically significantly associated with receipt of hospice inpatient care.</li> </ul>
Johnson et al., 2018  Quality score 32	Any specialist palliative care	Investigate whether access to specialist palliative care services ameliorates the effects of respondents' socioeconomic position on decedents place of death. Study reports	Patients (proxy)	Income (quartiles)  Qualifications	Receipt of care	<ul style="list-style-type: none"> <li>• Income was missing for 20% of respondents. Nearly 100% provided qualification status.</li> <li>• No evidence of association between income of respondents and access to care.</li> <li>• Respondents with a degree were more likely to access than those with no qualifications.</li> </ul>

		differences in access by respondent income.				
<i>Specialist and generalist palliative care</i>						
Cartwright, 1992  Quality score 22	Inpatient hospice (specialist palliative care)  GP and home nursing (generalist palliative care)	(i) Understand the impact of social differences in mortality on life before death; and (ii) examine the extent to which experiences differ between social groups in this time.	Patients (proxy)	Social class (I-V)  Definitions from 1980 Classification of Occupations.	Receipt of care  Symptoms  Material resources  Death awareness  Need for care	<ul style="list-style-type: none"> <li>More middle class admitted to private hospital or hospice than working class. No class difference in home visits from GP (adjusted for age) or receipt of home nursing help.</li> <li>More middle class had good quality of life in last year. More working class reported problems with costs of keeping home warm, adapting house to needs. More working class had financial problems.</li> <li>No class difference in symptoms apart from more dry mouth reported by working class; no difference in awareness of dying or being able to find all information wanted.</li> </ul>
Dixon, et al., 2015  Quality score 31	Community services (specialist and generalist palliative care)	Identify and explore systematic differences in access or outcomes, between geographical areas, settings	Patients (proxy)	Area deprivation (IMD)	Receipt of care  Need for care	<ul style="list-style-type: none"> <li>No evidence of a difference in receipt of care from Marie Curie Nurses, hospice at home, other nurses, or rapid response teams between areas of deprivation.</li> <li>Families of deceased who lived in more deprived</li> </ul>

		or different groups of service-users.				areas were statistically significantly less likely to say they received sufficient help and support, and to have received spiritual or emotional support.
Wilson, 2009  Quality score 26	Nurses (specialist palliative care)  District nurses (generalist palliative care)	(i) explore whether the lifestyle factors of a patient influences nurses' pain management decisions; and (ii) explore if post basic education and experience of pain and pain management in the clinical setting influences nurses' attitudes in relation to pain.	HCP	Occupation	HCP assessment of patients  Stigma	<ul style="list-style-type: none"> <li>Generalist nurses were significantly less likely to recognise the pain described by businessman than a construction worker with a history of drink driving.</li> </ul>
Koffman et al., 2007  Quality score 31	Any palliative care  Macmillan cancer (specialist palliative care)	(i) explore the awareness of palliative care and related services among UK cancer patients; and (ii) analyse	Patients	Area deprivation	Awareness Understanding	<ul style="list-style-type: none"> <li>Patients in the least deprived areas were 8.4 times as likely to recognise the term palliative care and 7 times as likely to correctly understand the role of Macmillan nurses than those in the most deprived areas.</li> </ul>

		the relationship between demographic factors and patients' knowledge-base				
Seale, et al., 1997  Quality score 28	NA (death awareness)	Report the prevalence of different awareness contexts and explore the causes of differences.	Patients (proxy)	Social class (I -V).  No reference or details given.	Awareness	<ul style="list-style-type: none"> <li>Being in a higher (I and II) social class increased the odds of someone dying in full open awareness by 2.66 times, compared to being in classes IV and V. This remained statistically significant for just cancer decedents but not non-cancer decedents.</li> <li>Those who died in an open awareness context were more likely to have died in a hospice.</li> </ul>
<i>Generalist palliative care only</i>						
Hanratty, Jacoby, and Whitehead, 2008  Quality score 32	GP services	(i) Analyse use of and payment for health and welfare services in the year before death for decedents in different financial circumstances; and (ii) determine their receipt	Patients	Perception of financial circumstances.  Annual household income	Receipt of care	<ul style="list-style-type: none"> <li>People who reported financial difficulties had more than an 80% increase in the likelihood of being a frequent attender of GP services and were less likely to pay for services. Paying for care was also associated with high use of GP services.</li> </ul>

		of relevant illness related state benefits.				
Barclay et al., 2003  Quality score 31	GP services	Compare palliative care training of GPs in deprived south Wales valleys with rest of Wales.	HCP	Geographic regions	HCP assessment of patients	<ul style="list-style-type: none"> <li>• There was no evidence of a difference between GPs in terms of palliative care training in areas of high and low social deprivation at any of the four career stages. Valleys GPs were older, longer qualified and more likely to be non-UK graduates.</li> </ul>

**Table 4: Studies using routine data**  
*HCP=Healthcare professional*

Author(s)	Care setting	Aims	Population	Socioeconomic measure	Access measure	Key findings relating to review questions
<i>Specialist palliative care</i>						
Allsop et al., 2018  Quality score 34	Inpatient and community hospice care	Understand how patient and organisational factors influence the duration of hospice-based palliative care prior to death.	Patients/ Hospices	Geographic regions (North, South, Midlands)	(Timing of) receipt of care	<ul style="list-style-type: none"> <li>On average, hospices in the North of England had a shorter median number of days between referral and death than those in Midland, London and South of England.</li> </ul>
Buck et al., 2018  Quality score 28	Hospice at home	Describe the care provided by a hospice at home service.	Patients	Area deprivation	Receipt of care	<ul style="list-style-type: none"> <li>Smaller proportion of referrals from most deprived area.</li> <li>Deprivation scores of those who received care were significantly lower than those of general population in all but one area.</li> </ul>
Burt et al., 2010  Quality score 35	Outpatient and community care	Understand the effect of age on use of services after accounting for need, including area deprivation.	Patients	Area deprivation (IMD)	Receipt of care	<ul style="list-style-type: none"> <li>No statistically significant association between receipt of specialist palliative care and area deprivation.</li> </ul>
Campbell et al., 2010  Quality score 32	Hospice at home	Explore how socioeconomic position influences access to hospice at home.	Patients	Area measures of:  Deprivation  Educational	Receipt of care	<ul style="list-style-type: none"> <li>Suggests that socioeconomic characteristics not service provision or cancer mortality predicts ward-level referral rate, including area measures of deprivation, social grade, and economic activity.</li> </ul>

				attainment Social grade Economic activity Household tenure		
Clark, 1997  Quality score 17	Hospice at home	Describe the use of a hospice at home service.	Patients	Area deprivation	Service capacity	<ul style="list-style-type: none"> <li>Patients living in the more deprived areas received twice as many visits at home as those in the less deprived areas. Statistical significance not reported.</li> </ul>
Grande et al., 2002  Quality score 32	Hospice at home	Understand differences between patients receiving hospice at home and not, in terms of their overall healthcare use.	Patients	Area deprivation (Townsend; Jarman)  Social class derived from Standard Occupational Class (SOC).	Receipt of care	<ul style="list-style-type: none"> <li>Patients referred to hospice at home came, on average, from less deprived areas than those who were not referred to hospice at home.</li> <li>No statistically significant difference in referrals by social class</li> </ul>
Gray and Forster, 1997  Quality score 29	Any specialist palliative care	(i) Provide district with information about their current service provision; and (ii) inform national debate about use of specialist palliative care services.	Patients	Social class (I- V) based on Office of Population Censuses and Surveys (OPCS) occupational classifications	Receipt of care	<ul style="list-style-type: none"> <li>The majority of cases in both groups (received/did not receive care) were in the lower social classes (Mm, IV and V) and that there were no significant differences between the two groups regarding receipt of care.</li> </ul>

London Cancer Alliance, Palle8 and Marie Curie (London Cancer Alliance) 2015  Quality score 26	Inpatient and community hospice care	Understand more about the provision of specialist palliative care in London	CCGs	Area deprivation scoring taken from 2011 London Cancer Alliance's audit exercise	Receipt of care	<ul style="list-style-type: none"> <li>Some CCGs in North East London had high relative deprivation scores and comparatively lower proportion of people with cancer who accessed community services. This association was less clear with inpatient units. Statistical significance not reported.</li> </ul>
Marie Curie Cancer Care and the Bevan Foundation (Marie Curie) 2014  Quality score 25	All specialist palliative care	Explore whether access to palliative care services may be shaped by people's socio-economic status, exacerbating existing inequalities in the incidence of diseases, as well as by factors such as age and diagnosis.	Patients	Area deprivation (no details on index used)	Receipt of care	<ul style="list-style-type: none"> <li>Nearly the same proportion in most and least deprived areas received care.</li> <li>For deaths from cancer, the proportion of people receiving SPC is slightly higher in most deprived quintile.</li> </ul>
<i>Other palliative/end-of-life care</i>						
Fisher et al., 2016  Quality score 26	Out of hours (generalist palliative care)	Describe patterns of usage of patients presenting to the out-of-hours	Patients	Area deprivation (IMD)	Receipt of care	<ul style="list-style-type: none"> <li>Patients contacting the OOH service with palliative needs were relatively less deprived than contacts for all other causes.</li> </ul>

		service and labelled by the service as 'palliative'.				
Hanratty et al., 2008  Quality score 23	Hospital (end-of-life care)	Explore the value of linked mortality and hospital activity data in palliative care research (by exploring the relationship between deprivation and hospital stays at end of life).	Patients	Area deprivation (Carstairs)	Receipt of care	<ul style="list-style-type: none"> <li>• Use of hospital services in the last year of life varied by area deprivation for patients with cancer and heart failure.</li> <li>• Residents of the most deprived areas with heart failure were more likely than patients from other areas to spend more days in hospital.</li> <li>• Patients with cancer from the most deprived areas were more likely to be admitted frequently but less likely to be amongst the longest staying patients.</li> </ul>

**Table 5: Studies using interviews**

HCP=Healthcare professionals

Author(s)	Care setting	Aims	Population	Socioeconomic measure	Access measure	Key findings relating to review questions
<i>Specialist and generalist palliative care</i>						
Kessler et al., 2005  Quality score 26	Hospice GP services	(i) Clarify the relationship between social class and place of death; and (ii) explore carer anxiety and barriers to control for people of a lower socioeconomic	Patients  Carers	Social class (I-V).  Taken from Standard Occupational Classification.	Attitudes  Relationships  Social resources  Material resources  Information seeking	<ul style="list-style-type: none"> <li>• Disadvantaged social class associated with having relatives close by and more available, expressing less desire for information, and passively receiving information.</li> <li>• Families often relied on their most forceful members, particularly children of higher social</li> </ul>

		position receiving palliative care.				<ul style="list-style-type: none"> <li>class, to help negotiate barriers to accessing care.</li> </ul>
Fergus et al., 2010 Quality score 29	Out of hours (generalist palliative care)	Identify key issues relating to out of hours care for palliative care patients, carers and professionals.	Patients Carers HCP	Area measures of:  Income Unemployment Social grade Household type Car ownership	Information resources  Relationships Communication Resistance to care Service organisation Gatekeeping	<ul style="list-style-type: none"> <li>The rigmarole - lengthy and difficult process - makes patients reluctant to access services.</li> <li>Some patients misunderstood the service, assuming transfer was automatic.</li> <li>Bad (stressful) experiences led to decision not to contact the service again and district nurses felt it hindered contact with GPs.</li> <li>There was a need for better communication and information sharing to improve decisions during out-of-hours care.</li> </ul>
Spruyt, 1999 Quality score 22	Community-based care (all palliative care)	Increase understanding of the Bangladeshi community's experiences of palliative care	Carers	Not formally measured but local area described as deprived and disadvantaged.	Communication  Costs Quality	<ul style="list-style-type: none"> <li>Issues with finances and re-housing influenced carers' experiences of supporting patients and their impression of the quality of formal healthcare services.</li> </ul>

		in East London.				
<i>End-of-life care</i>						
Hanratty et al., 2012  Quality score 30	End-of-life care (any)	Explore people's experiences of transitions between healthcare settings at the end of life.	Patients	Occupational class	Relationships Communication Attitudes Service organisation	<ul style="list-style-type: none"> <li>Most participants were from disadvantaged areas and the findings may reflect issues around socioeconomic experiences.</li> <li>Patients reported positive experiences with individuals but challenges negotiating transitions, particularly when system priorities were not aligned with patient priorities, in securing support across settings, and communication between HCP and patients.</li> <li>Authors did not note any differences in experiences between SE groups but SE experience was not the focus of the study.</li> </ul>

**Table 6: Studies using spatial methods**

Author(s)	Care setting	Aims	Population	Socioeconomic measure	Access measure	Key findings relating to review questions
Gatrell and Wood, 2012 Quality score 34	Inpatient hospice (specialist palliative care)	Visualise and understand geographic patterns of both the demand for, as well as the supply of, specialist inpatient hospices.	Hospices	Area deprivation	Availability	<ul style="list-style-type: none"> <li>There are 5.35 million adults living in areas of England and Wales that have higher than average deprivation and demand (cancer deaths) but below average access to inpatient hospice.</li> </ul>
Wood et al., 2009 Quality score 28	Inpatient hospice (specialist palliative care)	Assess the extent to which those living in particular wards in North West England have equity of access to adult inpatient hospice services.	Hospices	Area deprivation	Availability	<ul style="list-style-type: none"> <li>41% of wards in the North West where access was poor and demand relatively high were relatively highly deprived.</li> </ul>

**Table 7: Studies using economic analysis**

Author(s)	Care setting	Aims	Population	Socioeconomic measure	Access measure	Key findings relating to review questions
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Walsh and Laudicella, 2017  Quality score 30	End-of-life care (hospital)	(i) examine whether there is a socioeconomic gradient in end-of-life healthcare costs exist; and (ii) whether any observed disparities area underpinned by greater use of emergency admission amongst lower SES patients	Patients	Area income deprivation	Organisational resources (cost)	<ul style="list-style-type: none"> <li>• End of life healthcare costs in England are highest amongst cancer patients who live in more income deprived areas, largely due to the higher use of emergency service by these patients.</li> <li>• The most deprived groups have longer stays in hospital after an emergency admission.</li> </ul>
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### 4.3.2. Findings

The data collected from the included studies was not comprehensive enough to map onto each of the seven key stages of candidacy. Instead, four broader themes were generated, within which core concepts of candidacy were evident: identifying needs; taking action; local conditions; and receiving care.

#### 4.3.2.1. Identifying needs

The theme ‘identifying needs’ incorporates some of the barriers and facilitators to identifying a patient’s need for palliative care that relate to socioeconomic factors. These are further categorised into evidence from ‘patients’, ‘families’ and ‘healthcare professionals’.

##### *Patients*

Several sources suggest that patients from more socioeconomically disadvantaged backgrounds may have a greater need for palliative care (Burt et al., 2010, Cartwright, 1992, Clark, 1997, Dixon et al., 2015, London Cancer Alliance, 2015, Walsh and Laudicella, 2017). Two studies reported lower satisfaction with care among this patient group, indicating there may be a gap between the care patients need – or expect – and what they receive (Cartwright, 1992, Dixon et al., 2015). However, these studies did not find differences in the types of home palliative care services received across socioeconomic groups. Other evidence suggests that even when services are generally considered helpful, having unmet socioeconomic needs, such as a failure to be re-housed, can lead to dissatisfaction with services (Spruyt, 1999). This suggests that simply receiving a service is not sufficient for meeting the needs of different socioeconomic groups equitably. However, as very few studies of receipt of care adjusted for need, and some just used mortality as a crude measure (Campbell et al., 2009), it is difficult to examine in depth the relationship between need for services and use of them.

Few studies considered how patients in different socioeconomic positions might assess their palliative care needs. How aware patients are that they are dying may influence whether they *identify as a candidate* for palliative care. One study of 1662 caregivers found that patients in more advantaged social classes (I and II) were more likely to know they were dying, believe it was best to know this, and were fairly

accepting and content to talk about their death, compared to social classes IV and V (Seale et al., 1997). This contrasts with an earlier, smaller survey that found no class differences in death awareness or attitudes towards awareness (Cartwright, 1992). Both these studies are over twenty years old; it may be that societal attitudes towards death awareness have since shifted.

Evidence relating to attitudes towards palliative care services, which may also influence whether a patient sees themselves as a palliative care patient, was even more limited. One study found no evidence of a difference in attitudes towards hospice care between social classes (Kessler et al., 2005).

### *Families*

In several studies, family members helped to identify when a patient had care needs (Fergus et al., 2009, Hanratty et al., 2012, Kessler et al., 2005) such as:

...we could see a deterioration in my Mum... (Daughter of female lung cancer patient, Hanratty et al., 2012)

Kessler et al. (2005) found that disadvantaged families are more likely to have family members living close by and able to take time off work, whereas adult children in higher education or professional jobs tended to live away. Frequent familial contact may help to identify changing care needs but whether this is more likely for some patient groups possibly depends on the nature of socioeconomic disadvantage experienced by a patient. Additionally, having to take time off work could have dire financial consequences for those in a precarious socioeconomic situation before their family member became ill (Spruyt, 1999).

### *Healthcare professionals*

Few studies considered the assessment – or *adjudication* - of potential palliative care needs of patients from different socioeconomic backgrounds by healthcare professionals. One study considered whether HCP prejudices might lead to variations in care by examining pain assessments by nurses of patients in equal clinical scenarios with different socioeconomic and ‘lifestyle’ characteristics (Wilson, 2009). Although it is difficult to unpick judgements about ‘lifestyle’ from those about socioeconomic position,

the study suggested that district nurses are more likely to believe pain reported by a businessperson with a family than by an unemployed construction worker with friends drinking by his bedside. No differences were found for specialist palliative care nurses. Assuming training is a key factor in overcoming prejudices and assessing care needs, differences in HCP palliative care training across socioeconomic areas may be important. Only one study looked at this, finding no evidence that GPs in the socially deprived Valleys area of Wales had lower levels of generalist palliative care training than those in non-Valleys area (Barclay et al., 2003).

There was more evidence about organisational barriers – *local operating conditions* – to assessing patients. These included being unavailable to visit (Buck et al., 2018, Kessler et al., 2005), having little patient information (Buck et al., 2018, Fergus et al., 2009), or not having time to talk (Cartwright, 1992, Hanratty et al., 2012). Cartwright (1992), for example, found that working class people were less likely to feel that the general practitioner had had time to discuss things. It is unlikely resource-related challenges are unique to socioeconomic disadvantaged populations; examples were found in both deprived and mixed communities. Nonetheless, these barriers may be exacerbated when they interact with socioeconomic characteristics, although in these studies only Cartwright (1992) explicitly made this connection.

#### 4.3.2.2. Taking action

Whether someone receives the care they need depends on the abilities of patients, families, and healthcare providers to take steps to secure that care. This ability to ‘take action’ may be influenced by factors relating to socioeconomic position, with socioeconomically disadvantaged groups and communities potentially finding it harder to *navigate* this process because of differences in informational, social, and material resources.

##### *Information*

Several studies reported differences in information resources between socioeconomic groups. This included disadvantaged patients being less likely to recognise the phrase palliative care or correctly understand the role of Macmillan nurses (Koffman et al., 2007), showing less desire for information or

preferring to “passively” acquire it (Kessler et al., 2005) finding it difficult to ask for information (Hanratty et al., 2012), and misunderstanding the role of an out of hours palliative care service (Fergus et al., 2009).

### *Social*

The relationship between socioeconomic position and social support for patients with palliative care needs in the UK is less clear. There were numerous examples of families helping to secure care and sometimes this had a socioeconomic dimension to it; Kessler et al (2005) found that patients often relied “on their most forceful members, particularly children of higher social class” to successfully demand care services, such as access to a hospice bed. However, Johnson et al. (2017) found that household income of carers was not related to access to palliative care, but higher qualifications were, particularly having a degree. These findings suggest that the ability to navigate care successfully may have a stronger link with having a highly educated, possibly younger, care advocate, rather than the patient’s socioeconomic position. Importantly, it is not necessarily that patients and carers experiencing disadvantage do not ask for care, but that sometimes requests appear to go unheard. In one study of Bangladeshi carers in East London, a carer in precarious social circumstances reported not receiving formal support even after they “begged the authority for help” (Spruyt, 1999, p.126), and only received help after there a fire broke out in their kitchen.

### *Material*

There were no explicit examples of care being prevented due to a patient’s material living conditions. However, patients living in more deprived areas may have less suitable home care environments. For example, Cartwright (1992) found that more working class than middle class patients had difficulties overcoming barriers to care related to housing, sometimes financially driven. Elsewhere, staff reported challenges delivering hospice care in “a home environment that was unsuited for end-of-life care” (Buck et al., 2018, p.4). Whether these prevent patients from receiving services, affects overall care quality, or increases admissions to hospice or hospital inpatient wards is unclear.

### *Resistance*

Given the evidence suggesting socioeconomic differences in informational and material resources, higher resistance may be more likely among disadvantaged groups. However, these studies rarely explored this potentially important component of healthcare access. Buck et al. (2018) found that approximately a quarter of a hospice service's annual care episodes were declined by patients, although the socioeconomic distribution of this was not reported. Hanratty et al. (2012) also reported that one patient, probably living in a disadvantaged area, asked for fewer health visitors because they interfered with her day. As a lone example, it is difficult to extrapolate findings to a social group more broadly. There is clearly a gap in the research literature about whether certain social groups are more resistant to palliative care than others, as well as how resistance emerges and is resolved in interactions between professionals and patients.

#### 4.3.2.3. Local organisation

Interactions between healthcare professionals and patients or families partly depend upon the local organisation of health services and the alignment of these services with patient preferences. This theme relates largely to the *permeability of services* and *local operating conditions* that contextualise access to care.

Patients in a deprived area of Scotland were put off accessing out of hours palliative care, sometimes because they did not want to see a 'strange' doctor or felt unable to go through the 'rigmarole' of the over-the-phone assessment (Fergus et al., 2009). Other patients tried, and sometimes failed, to assert preferences that conflicted with organisational processes and restraints (Fergus et al., 2009, Hanratty et al., 2012). For example, the assumption that everyone gets a hospice bed when they are dying held by patients who were socioeconomically disadvantaged was in contrast to the reality of scarce resources and limited referral options offered by generalist providers (Kessler et al, 2005). Scarcity was also evident in reports that a hospice at home service was "unable to provide episode of care" about half of the time, although the socioeconomic pattern to this is unknown (Buck et al., 2018, p.e26).

There are regional variations in England in the proportion of areas that are highly deprived and have high mortality but are over 30 minutes drive from a hospice inpatient unit (Gatrell and Wood, 2012, Wood et al., 2004). This highlights the importance of local context – for example, the distance to the nearest

hospice and availability of alternative community-based services - in understanding scarcity. Regional differences are also evident in times between referral to hospices and death, with the North of England – a more disadvantaged region on average – seeing shorter duration of time in hospice care than the Midlands or South of England (Allsop et al., 2018). Nonetheless, a study of a hospice at home service in Manchester found increasing deprivation was associated with lower referral rates when care provision is controlled for (Campbell et al., 2009), suggesting that service variability is only part of the story.

#### 4.3.2.4. Receiving care

Most studies included in this review reported findings on receipt of palliative care and socioeconomic position. This evidence is categorised below into ‘receiving generalist care’ and ‘receiving specialist care’.

##### *Receiving generalist care*

Professionals in non-clinical services, such as GPs or hospital clinicians, can be generalist palliative care providers in their own right; access to them increases the likelihood of receiving some palliative care. Using hospital services, particularly emergency care, at the end of life is consistently associated with being socioeconomically disadvantaged (Hanratty et al., 2008a, Marie Curie, 2014, Walsh and Laudicella, 2017). A survey also found that patients with financial difficulties were 80% more likely to be frequent attenders of GP services in the last year of life, compared to those who were ‘comfortable/doing alright’ (Hanratty et al., 2008b). A smaller study found no differences in use of GP services between middle and working classes, once adjusted for age, and no differences in the number visited by a nurse at home in the last year of life (Cartwright, 1992). The contrasting results between this and Hanratty et al. (2008b) study may reflect changes in demands for healthcare services in the sixteen years between them. Occupational class and perception of financial difficulties are also very different measures of socioeconomic position; it may be that Hanratty et al. (2008b) study drew out differences particular to income that are harder to pick up when using the much broader measures of working or middle class.

In contrast to both those studies, patients using out-of-hours service were more likely to be in less deprived areas in one study (Fisher et al., 2016), which was consistent with findings suggesting patients in a socially deprived area were put off using out of hours care because of perceived barriers to obtaining a visit from a clinician (Fergus et al., 2009). Patients using out of hours care often have to be assessed over the phone before they can speak to a clinician; in contrast, generalist services where patients have more control over how and when they can see a clinician seem to be more accessible - or *permeable* - for patients who are socioeconomically disadvantaged.

#### *Receiving specialist palliative and end-of-life care*

Just over half of findings (9/16) relating to receipt of specialist palliative care found no evidence of a difference between socioeconomic groups, although this may depend on a number of factors (Addington-Hall and Altmann, 2000; Addington-Hall et al., 1998; Burt et al, 2010; Grande et al, 2002; Dixon et al., 2015; Gray and Forster, 1997; Johnson et al, 2018; London Cancer Alliance, 2015; Marie Curie, 2014). There was a trend for findings based on survey data to suggest no evidence of a difference in receipt of specialist palliative care between socioeconomic groups (Addington-Hall and Altmann., 2000; Addington-Hall et al., 1998; Burt et al, 2010; Dixon et al., 2015; Johnson et al, 2018). A similar trend was found for findings based on individual measures of socioeconomic position (Addington-Hall and Altmann, 2000; Addington-Hall et al. 1998; Grande et al, 2002; Gray and Forster, 1997; Johnson et al. 2018), and from studies using national representative samples (Addington-Hall and Altmann, 2000; Addington-Hall et al., 1998; Cartwright, 1992; Dixon et al, 2015; Johnson et al, 2018).

In contrast, just over half of findings based on routinely collected data (Allsop et al, 2018; Campbell et al, 2009; London Cancer Alliance, 2015), on an analysis of areas or regions (Allsop et al, 2018; Buck, 2018; Campbell et al, 2009; Grande et al, 2002; London Cancer Alliance, 2015), or which used local data (Buck, 2018; Campbell et al, 2009; Grande et al, 2002; London Cancer Alliance, 2015) suggested patients who were socioeconomically disadvantaged were less likely to receive specialist palliative care.

#### 4.4.Discussion

This synthesis identified moments throughout the access process that might be experienced differently by patients belonging to different socioeconomic groups. Encouragingly, there is evidence that disadvantaged patients in the UK may not always be less likely to receive a referral into specialist palliative care. However, the difficulty of identifying and adjusting for differences in need when measuring receipt of care substantially limits the strength of this finding. Whitehead and Dahlgren (2006, p.12) argue that an important goal in health care equity is to match services to needs, which “may very well result in large differences in access and use of services between different socioeconomic groups, favouring the more disadvantaged groups in greatest need”. However, this review reiterates the finding stated elsewhere that socioeconomic differences in palliative care needs at a population level are not well understood and generally poorly accounted for in the UK literature (Burt, 2011).

The findings place the UK in somewhat of a contrast to other countries when it comes to access to specialist palliative care for socioeconomically disadvantaged groups. A recent review of global use of specialist palliative care amongst this population group concluded that socioeconomically disadvantaged populations are significantly less likely to access specialist palliative care (Davies et al., 2019). Most research comes from the United States, where healthcare services differ to those from European countries and where socioeconomic experiences are closely tied to ethnicity and race. Nonetheless, studies in Italy and Belgium have also linked socioeconomic position – specifically higher education - with access to specialist services (Beccaro et al., 2007, Bossuyt et al., 2011); a more recent study in Denmark did not, however, find a similar association with income (Neergaard et al., 2013). Along with differences between countries, the variability of findings within the group of UK-based settings suggest that the reasons for differences go deeper than the country of care. No methodological difference could be found to account for this in the synthesis above. This warrants further examination of the importance of the local setting and organisational context in determining whether receipt of specialist palliative care is fairly distributed between socioeconomic groups. Related to this is the potential association of socioeconomic position with other local population characteristics such as age, gender, or ethnicity, something that few studies considered, an exception being Spruyt (1999).

The process and experience of accessing palliative care undoubtedly differs in different settings across the UK. In England, for example, both the provision of voluntary hospice care and the number of people identified on GP registers as needing palliative care support varies widely between areas (Hospice UK, 2016, Harrison et al., 2012). Regional responsibility for commissioning NHS palliative care services also means the scope and scale of palliative care within the NHS can differ by place; only 37% of hospitals, for example, provide face-to-face access to specialist palliative care at least between 9am-5pm Monday to Sunday (Royal College of Physicians, 2016). This review found that certain types of services – hospital and GP services – were easier to access for disadvantaged populations than other services such as out-of-hours care. It is not clear whether there is an optimum way of organising services that overcomes some of the issues related to socioeconomic position and accessing palliative care. Given this possibility, there is an argument for not trying to study the effect of patient socioeconomic characteristics in isolation from other factors but rather consider how they may influence a process within a specific context or setting.

This review presented access to palliative care as a process of negotiation: patients *identify* their needs and then *navigate* their way to *appear* at a service, where healthcare professionals *adjudicate* whether they are a suitable candidate for care, and *offers* of care are made and accepted or rejected. The *permeability* of services – the ease with which they can be accessed – and the *local operating conditions* are two additional components that influence this. Although the sparse literature had to be synthesised under broader categories, these concepts of ‘candidacy’ were woven in throughout. This approach helped to identify the different ways a patient’s palliative care needs may be identified and acted upon, depending upon the socioeconomic group in which they fall. For example, evidence suggests that some patient’s ability to take action was limited by informational resources or services not aligning with care preferences. In placing the relationship between patient and provider at the centre of this experience, this review distinguishes itself from previous similar reviews that tended to categorise issues without exploring their interactions (Lewis et al, 2011). Nonetheless, the limited available evidence from the UK prevents any definitive conclusions about the usefulness of the candidacy model for understanding access to palliative in that setting. It is still difficult to say how the influence of one factor on access might depend upon its relationship to another issue. For example, there was little evidence about the interaction between the way professionals assess the care needs of patients belonging to different socioeconomic

groups, how those patients assess their own needs and present themselves to services, and any resource or capacity issues in healthcare services. Further research into how socioeconomic factors influence these interacting factors is necessary before beginning to consider whether access to hospice care is fair between socioeconomic groups in the UK.

### *Limitations*

Sparse evidence on dimensions of access other than receipt of care is a significant limitation to this review, as the question of how and why different factors relating to socioeconomic position influences access to palliative care remains largely unanswered. The large time span covered in this review (1993 to 2018), in which time there have been changes in healthcare organisation, demographics, and economics, also makes it difficult to synthesise findings.

Difficulties comparing study quality, in particular accounting for many of the studies not closely examining the role of socioeconomic position was a further limitation. Additionally, deciding where the process of identifying candidacy begins is complicated with palliative care given that referrals tend to be initiated by healthcare professional rather than by patients (Hui et al., 2016) but some clinicians are reluctant to do this (Beernaert et al., 2015, Broom et al., 2013, Clayton et al., 2005). This is compounded by access to palliative and end-of-life care probably occurring towards the end of a much lengthier experience of accessing healthcare. Further research might benefit from exploring how earlier experiences of accessing healthcare contributed to experiences at the end of life.

#### **4.4.1. Summary**

This systematic review of the literature in the UK relating to socioeconomic position and access to palliative care is the first of its kind. It revealed that available evidence on socioeconomic differences in receipt of palliative care does not follow the same pattern as evidence from global reviews, with many studies finding no evidence of a difference in receipt of care between socioeconomic groups. However, the variability in findings, which could not be easily explained by methodological differences, suggests that better understanding of the local conditions that either facilitate or deter access to palliative care in the context of socioeconomic disadvantage is warranted. There are significant gaps in understanding

about how socioeconomic factors influence access to palliative care in the UK, particularly those factors influencing healthcare professionals' assessment of need for care and how this interacts with resources, capacity, and other contextual conditions.

The remainder of the thesis seeks to address some of these gaps, using a methodological approach suited to capturing the real-life context in which hospice care is accessed. As described in the following chapter, this study draws on quantitative and qualitative methods to obtain stronger and more certain evidence about the extent and nature of the relationship between socioeconomic position and access to hospice care.

# Chapter 5. Methodology and Methods

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## 5.1. Introduction

There are several gaps in understanding about whether and how socioeconomic factors influence access to hospice care in UK settings. For instance, there is uncertainty about the association between socioeconomic position and use of hospice care. While most studies included in the systematic review in the previous chapter found no evidence of an association between socioeconomic position and use of specialist palliative or end-of-life care in the UK, others suggested that use of this care decreases with worsening socioeconomic position. Questions also remain about how circumstances relating to socioeconomic position may influence access to hospice care. The available evidence from the UK points towards potential difficulties identifying need for care among more socioeconomically disadvantaged populations and taking action to seek and provide that care. However, there is a notable lack of evidence about how socioeconomic circumstances may influence healthcare professionals' identification and assessment of need for referral to hospice care. Additionally, while organisational and other local contextual conditions are likely to influence access to hospice care, it is unclear which conditions facilitate or deter access in the context of socioeconomic disadvantage.

This research project is designed to address this shortfall by investigating whether and how access to hospice care is related to socioeconomic position, within a UK context. It is designed in such a way as to identify and explore the contextual conditions to this access, including the organisational and other local contexts to hospice care, aiming to fill some of the outstanding gaps in evidence summarised above.

The interest in organisational and local conditions to accessing hospice, among other things, calls for an approach to studying socioeconomic circumstances that looks beyond individuals and considers the experiences connected to areas or organisations working within particular settings. Social deprivation, a measure of area socioeconomic position, offers a means by which to do this. Studying the experiences of healthcare providers involved in hospice referrals working in socially deprived areas, and identifying

the conditions in which populations in those areas access hospice care, will help provide answers to the question of how socioeconomic position and access to hospice care are related.

### **5.1.1. Research question**

How is socioeconomic position related to accessing hospice care in UK settings?

### **5.1.2. Aims**

- (1) Explore the association between referrals to hospice care and area social deprivation, and the influence that provider and population characteristics have on this.
- (2) Explore the factors influencing how healthcare professionals generate, and respond to, hospice referrals in the context of social deprivation.

## **5.2. Research philosophy**

The research question and aims of this study reveal something about the philosophical assumptions and beliefs I hold, and which underpin this research. The interest in how factors influence phenomena imply an interest in causality, in the ways in which different entities are related and the effect this relationship has on the social world. In this study the causes of interest are those influencing hospice referrals in socially deprived areas. However, the process of referrals – and how factors related to socioeconomics might influence this – is not an observable phenomenon. An outcome attached to this process can be measured (referral rates, for example) and people may have experiences attached to this process, but the process itself is obscured from our direct experience and observation; it is an understandable but intangible reality.

This belief about reality – my ontological view of the world – draws upon the philosophy of critical realism (Bhaskar, 1975). This is a philosophical view of reality as layered rather than flat, with one empirical layer, one that is actual, and one that is real (Bhaskar, 1975). Paraphrasing Bhasker (1975), Easton (2010) describes the ‘empirical’ domain as that in which observations are made and experienced,

and the ‘actual’ as where events actually occur, but they may not be observed or may be interpreted differently. Finally, the ‘real’ domain consists of the generative mechanisms producing these events, and subsequent observations (Easton, 2010). This depiction accepts that an objective reality does exist, but is shrouded from our view and our immediate experiences, which are situated in the empirical domain. In recognising this distinction, a critical realist perspective is also one that accepts the existence of a socially determined reality alongside that which exists independent of human consciousness (Danermark et al., 2002). This draws upon aspects of other ontological positions that are sometimes seen as diametrically opposed, the positivist and interpretative paradigms (Bunniss and Kelly, 2010). In neither fully accepting nor rejecting these paradigms, critical realism seeks an alternative way to think about and obtain knowledge about the social world, in other words an alternative epistemological approach. Epistemology, as defined by Crotty (Crotty, 1998), is the theory of knowledge that defines the type of knowledge it is possible to have, and which is legitimate.

An important facet of this epistemological approach is that knowledge of an objective reality – as depicted within a critical realist philosophy - is fallible and always subject to revision (Sayer, 2000). This is because, in this worldview, objective reality itself is unknowable so understanding of it can never be absolute. While accepting this, knowledge about that reality can still be sought, and it is possible to theoretically reason about the causes of phenomena by studying the effect they have in the empirical layer of reality. A consequence of this is that knowledge can be dependent on theory but not determined by it (Danermark et al., 2002). That is, we can draw theoretical conclusions based on our observation and interpretation of events and outcomes but these theoretical conclusions are not fixed.

This acknowledgement that a theoretical understanding of the world can change is also premised on the study of the social world being the study of open systems, those which are complex, contextual and cannot be controlled for the purposes of experimentation (Danermark et al., 2002). Given this, theory developed from the study of events (triggered by unobservable causal mechanisms) cannot make lawlike generalisations, because it cannot fully incorporate all possible causes of that event (Sayer, 2000). However, critical realist thinkers are keen to avoid a descent from this position into relativism, and challenge the suggestion that a rejection of lawlike generalisations means any interpretation of the ‘truth’ is relevant (Groff, 2004). As stated by Danermark et al (2002, p.15), “all knowledge in fact is fallible and open to adjustment. But not all knowledge by far is equally fallible.” This statement captures the

important link between the epistemological position within critical realist philosophy to the research methodologies and methods harnessed to study the social world. The task of the critical realist researcher is to generate knowledge and strengthen understanding by studying observations in the empirical domain, using this understanding to make valid statements about potential events and causal mechanisms underpinning those observations. To build theory from these statements, the conditions in which events occur (and which power the causal mechanisms) must be identified (Easton, 2010).

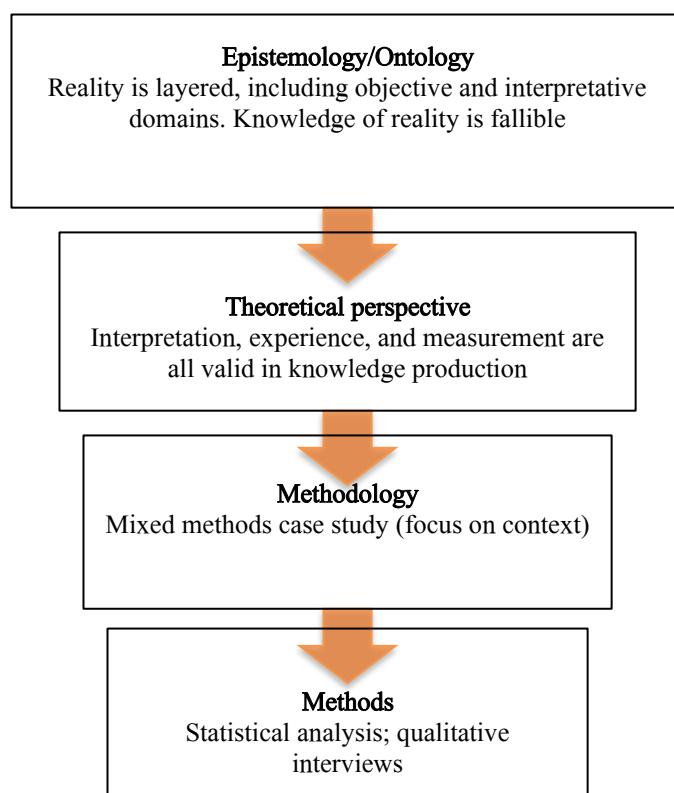


Figure 4. Steps from philosophy to methods (adapted from Crotty (1998))

Adapted from Crotty (1998), Figure 4 is a diagram of the steps between epistemological and ontological thinking to the choice of research methods. Applied to this study, and to myself as a researcher, the view of reality as objective but knowledge of that reality is fallible determines all other steps. The theoretical perspective, as defined by Crotty (1998), reflects the beliefs that must follow from the epistemological position; in my case, this includes the belief that both experiences and objective measurements are valid ways to obtain knowledge, as they can reveal something about the (partly socially determined) knowledge of the events and outcomes produced by the objective, unobservable reality. Later in this

chapter, I explain how the methodology of this study, and the methods used, are a natural extension of these epistemological and theoretical perspectives. Briefly, this study uses a mixed methods multiple case study approach that can capture different types of data relevant to our knowledge of reality, specifically seeking to incorporate contextual conditions into explanations about hospice referrals.

## 5.3. Methodology

### 5.3.1. A case study approach

Access to hospice care is a complex process potentially influenced by many factors and contextual conditions. As a research approach suited to investigating complex phenomena, case study is an appropriate methodology for studying it (Walshe et al., 2004). As an investigative method, case study has been around since the early 20<sup>th</sup> Century but gained a foothold in mainstream educational research in the 1970s amid growing interest in alternative research approaches to positivist experimental sciences (Simons, 1996). These alternatives tended to be underpinned by the belief that studying variables within a controlled experimental environment could provide only a limited view of the world (Simons, 1996). Case study was one of many emerging methodologies that invited a more contextualised understanding of phenomena, recognising the real-world setting in which these phenomena occur (Yin, 2018, Yin, 2014). Today it is a research method used in many disciplines (Wynn and Williams, 2012, Easton, 2010), with growing use in healthcare research, particularly in studies of palliative care (Brogan et al., 2019, Walshe et al., 2008, Walshe et al., 2004). While there is increasing interest in this approach, case study has arguably been overlooked within applied healthcare research in favour of experimental trial designs, despite being well suited to capturing the complexity inherent to many healthcare interventions (Paparini et al., 2020, Walshe, 2011).

One of the reasons why case study has been overlooked as a research approach within healthcare may be the difficulty defining what a case study is and how best to approach doing one. A widely accepted definition of case study research is that it is the study of a complex phenomenon in a real-life or naturalistic setting, focusing on understanding the context in which something occurs (Crowe et al., 2011, Simons, 2009, Yin, 2014). This definition focuses on the activity of a researcher within case study

research, defining what is done rather than specifying what a case study looks like. This inherent ambiguity facilitates the study of a wide variety of types of cases, from individuals to countries and from single decisions to systematic processes. A case study is bounded by the definition of the case itself, which delineates between the phenomenon of interest and phenomena that fall outside the case (Merriam and Tisdell, 2015, Miles and Huberman, 1994).

Given this broad definition – a study of a bounded phenomenon in its real-life context – case studies can be underpinned by different research philosophies and approached using a variety of methods. In practice, many case study researchers primarily use qualitative methods. However, the widely cited case study methodologist Robert Yin is explicit in his recognition that both quantitative and qualitative methods can be used in case study research (Yin, 2014) Others have similarly argued that the flexibility inherent to case study research means it “is a bridge that spans the research paradigms” (Guetterman and Fetters, 2018).

The choice of methods depends on the specific purpose of a case study, the use of theory in that study, and the philosophical beliefs of the researcher(s) involved. Yin (2018) proposes three broad classifications of case study: descriptive, exploratory, and explanatory. Each type can respond to different research questions ranging from what (exploratory or descriptive), how much (descriptive) or how and why (explanatory) (Yin, 2018). Yin (2018) also describes the difference between exploratory and explanatory case studies in theoretical terms; exploratory studies tend to start with few theoretical ideas about the phenomenon whereas explanatory studies begin with a theory and then set out to test it. Such a sharp delineation of these two approaches is probably an inaccurate reflection of the reality of most case studies, where researchers will move between theory and data in a much more iterative way. Yin and others have recognised that many case studies are likely to involve both exploratory and explanatory approaches (Yin, 2014, Eisenhardt, 2007). In an article about building theory from case study, for example, Eisendhardt (2007) states “it is impossible to achieve [the] ideal of a clean theoretical slate” (p. 536). Clarifying how much is on that slate at the outset of the study will help identify the type of case study best suited for that research.

### 5.3.2. Using a theoretical model

This study began without a ready-made established theory explaining the relationship between access to hospice care and socioeconomic position, and how factors influence referrals to hospice care in socially deprived areas. There were, however, relevant theoretical models in the wider literature on access to healthcare services. As described in Chapter 3 these models suggest access to healthcare is influenced by factors relating to healthcare professionals, services, and patients. The ‘candidacy’ model of accessing healthcare describes a process of negotiating access through multiple interactions between professionals and patients contextualised by local conditions in which they operate (Dixon-Woods et al., 2006). As this candidacy model was developed during an evidence synthesis specifically looking at access to healthcare for socioeconomically disadvantaged populations (Dixon-Woods et al., 2006), it was built around similar concepts that ground this study: access and socioeconomic inequity.

While this model is an appropriate starting point, it can go only so far in its usefulness for explaining the relationship between hospice care and social deprivation. The potential weaknesses in this model have already been explored in earlier chapters. This includes the chronology of candidacy (beginning at the patient identifying a need for healthcare) potentially not fitting the pathway to hospice referral, which may be triggered by a healthcare professional. Additionally, in its original conception, the model arguably neglects the influence of wider society, i.e. the macro or structural influences on social inequities in healthcare access. While these limitations do not call for an outright rejection of the model, they indicate that the model may potentially neglect some factors important in influencing access to hospice care. For this reason, I approached this study as a predominantly *exploratory* case study seeking to explore the association between social deprivation and hospice referrals. I then sought to incorporate *explanatory* elements when considering the question of how these factors influence access to hospice care, including their influence on referrals.

### 5.3.3. Propositions

Yin (2014) proposes that the theoretical starting point of a case study be made explicit early on in one or more short statements - propositions - that outline the possible relationships between the variables or phenomenon of interest. These statements can help to clarify the theoretical base from which a study

begins, provide boundaries around the case, and signal to researchers the type of data to collect (Yin, 2014). They are generated by those undertaking the research and are specific to each study. They do not stay fixed and are typically refined and adapted following data analysis to reflect the findings (Yin, 2018). In this way, they are different to fixed hypotheses typically rejected or accepted in statistical studies.

The initial propositions for this research were first drafted after considering research evidence from other countries, and exploring findings from studies in the UK through the lens of the candidacy framework. They convey my understanding, at that time, about how factors may influence access to hospice care for people in socially deprived areas. Reflecting the initial exploratory approach of this study, the early versions of these propositions were deliberately broad:

*Proposition 1*

Hospice referrals are associated with social deprivation, accounting for the effect of patient, population, and area characteristics.

*Proposition 2*

Referrals to hospice services in socially deprived areas are driven both by the way services are delivered and how healthcare professionals and patients interact with one another in those areas.

These propositions – written at the outset of the study – are returned to later in this thesis when discussing study findings.

In their initial form, the propositions identified which data needed to be collected. To explore them further, data on hospice referrals, area demographics, and patient demographics were required, as well as data about the experiences of hospice referrals and interactions with patients. These requirements are reflected in the study objectives:

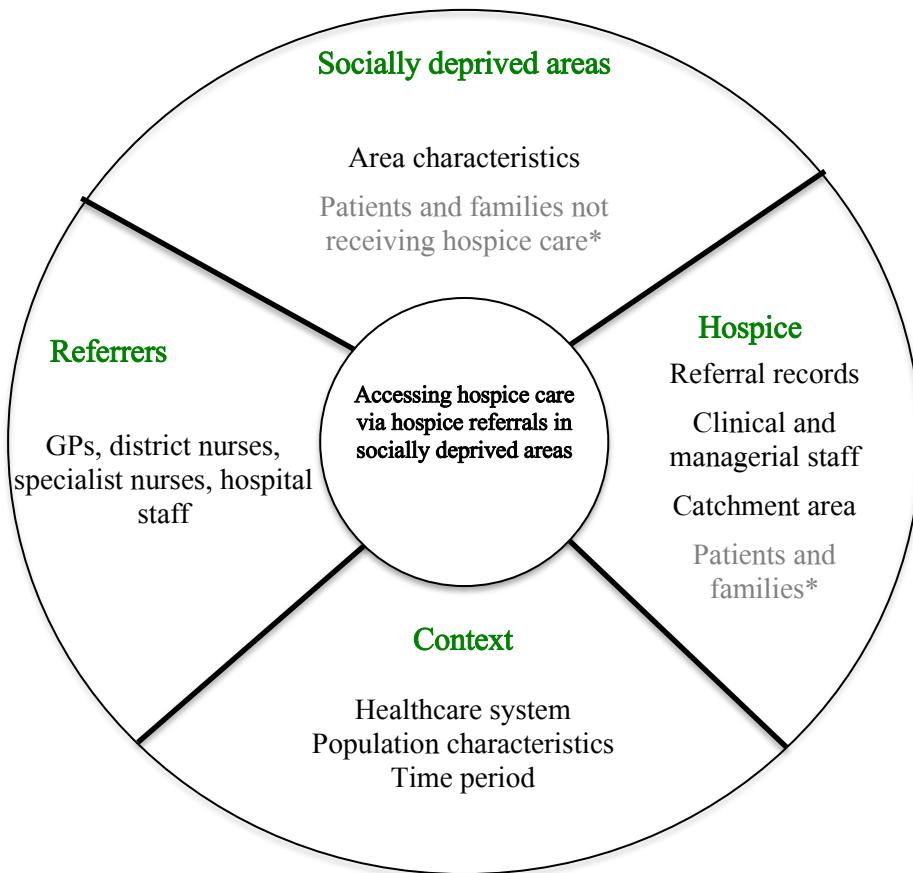
1. Compare hospice referral rates across different areas of deprivation, whilst accounting for any differences in demographics and other area characteristics.

2. Link data on the social deprivation of areas where patients live to the service they were referred to, who referred them, their diagnosis, and other patient characteristics.
  
3. Interview healthcare professionals to gather data on their experiences of generating or responding to hospice referrals in more socially deprived areas.

#### **5.3.4. Bounding the ‘case’**

Just as propositions describe the focus of a case study, case definitions describe the boundaries or limits to a case (Yin, 2018, Merriam and Tisdell, 2015). While defined at the outset, the boundaries of a case can be revisited and refined as a researcher comes to better understand it during the study (Yin, 2018). Nonetheless, the concept of the case should be moulded enough to guide, structure, and limit the data collection. In this study, the case was *the accessing of hospice care via hospice referrals in socially deprived areas*.

A hospice’s catchment area provided a geographical boundary to each case, focusing on the experiences of healthcare professionals within that geographical area. The time period of the case was defined by the period for which each hospice could provide reliable referrals data. Consequently, this was a retrospective case study, with data relating to a time period in the (recent) past. Data were collected about patients, healthcare professionals and populations living or working within a specific area and in a specific (retrospective) time period. The socially deprived areas and the healthcare providers with a direct influence on hospice referrals were the focus of the case. The wider health services and populations within a hospice’s catchment area did not have a direct influence but nonetheless contextualised the case (Figure 5). To summarise, at the outset of the study the case was bounded by time, geographical space, and direct involvement in hospice referrals. Much of the relevant context to the case emerged more iteratively as the research progressed, often during exploratory analysis and interviews with healthcare professionals.



\*Patients and families were included in the original case definition but difficulties with recruitment meant they were not included as interview participants (see section 5.6.2.2)

**Figure 5: Case definition**

## 5.4.Mixed methods

The data used for this research was about social deprivation, hospice referrals, and the experiences of healthcare professionals. Some data came from hospice referral records whilst other datasets were generated in interviews. Given this, a mixed methods approach that could accommodate quantitative and qualitative data was the most appropriate for this study.

### 5.4.1. The philosophy of mixed methods research

Mixed methods research embraces quantitative and qualitative methods as diverse but compatible techniques for doing research (Creswell, 2009). While acknowledging the distinct philosophical positions of these approaches, a mixed methods approach considers multiple viewpoints as useful for research and therefore seeks a workable solution between them (Johnson et al., 2007). While commonly associated with a pragmatist philosophy, critical realism also provides a philosophical framework coherent with mixed methods research (McEvoy and Richards, 2006). Because this philosophy accepts that an objective reality exists but that we must interpret this reality (and therefore accepts that our knowledge is at least partly socially determined) it offers a framework inclusive of attempts to measure phenomena objectively and explore different interpretations of those phenomena (McEvoy and Richards, 2006). Using both approaches, researchers can help build a picture of reality that is feasible and plausible, given what the observations about it suggest.

### 5.4.2. Mixing methods in this study

Mixed methods research can serve different purposes depending on the aims of a study. Using categorisations proposed by Creswell (2009), this case study followed a sequential explanatory design, with the different types of data collected separately and the findings from one set of data used to explain findings from another. This study used qualitative data about the experiences of healthcare professionals involved in hospice referrals to help expand and explain findings from a quantitative analysis of hospice referrals data. The analysis drew on findings from both types of data to try to understand outcomes in the context of experiences particular to that case. The ‘mixing’ of methods occurred in two places: when using the quantitative results to partly guide the qualitative data collection and in using qualitative data

to try to explain how some factors influenced the number of hospice referrals in different areas of deprivation. The data collection remains separate.

In its contribution to overall findings, the qualitative component was arguably the more dominant method in this research. However, the statistical analysis of hospice referrals made a fundamental contribution to understanding access to care. There was also considerable effort in collecting, managing, and analysing this type of data. Taking this into account, the research work required is more or less equivalent for both methods across the course of the study.

### 5.5. Multiple case study

So far in this chapter, I have described this study as an exploratory case study using mixed methods to answer related but distinct questions about access to hospice care in socially deprived areas. A subsequent decision concerned the number of cases to study. This study included three cases to investigate the phenomenon of accessing hospice care in socially deprived areas under different circumstances.

Case study is concerned with looking at phenomena in-depth, over time, and with consideration of how the context in a particular case relates to the phenomenon of interest (Yin, 2012). In some studies, it is beneficial to look at the same phenomenon in different cases. The use and purpose of multiple cases is partly determined by understanding of generalisability in a study. This is evident in the distinct approaches to multiple case study research described by two key case study methodologists Robert Yin (2014; 2018) and Robert Stake (2006), who come from contrasting philosophical positions.

For Yin, the benefit of using multiple cases is largely theoretical, suggesting that multiple cases help generalise findings to theory (Yin, 2014). Adopting a post-positivist stance, experimental logic is used to select cases. Cases are selected because they are predicted to either replicate findings or produce conflicting findings, based on a theoretical understanding of the phenomenon of interest. Decisions about case selection are made transparent by stating the theoretical 'starting points' in the form of propositions, such as those already described in this study. Stake (2006) also supports the use of multiple cases, describing these forms of case study as collective case studies. Coming from a more constructivist point

of view, he places less emphasis on generalisability and focuses on comparing and contrasting case findings without losing what is particular to each case.

This approach taken in this study was closer to that proposed by Yin. The study addressed the question of whether and how socioeconomic position is related to access to hospice care, specifically looking at hospice referrals in socially deprived areas. Selecting cases based on their differences facilitated investigation of how differences in the local conditions to hospice care helped to drive the way hospice care was accessed in these cases. In identifying similarities between cases, there was scope for generalising findings across cases whilst recognising the contribution of unique contextual conditions within each case.

Although recognising the opportunity for generalising in a multiple site case study, the approach taken in this study departed from Yin in some of the language used around predictability and replication. The replication logic proposed by Yin (2014) suggests that if results predicted by theory are empirically observed then it is possible to draw conclusions about the effect of the variable of interest. These conclusions could be strengthened by a second case study whereby the variable was different or absent and a correspondingly different set of observations was made, suggesting that the theory upon which the prediction is based is correct. This study was underpinned by a philosophical stance that recognises some variables may have a powerful and widely-applicable influence on access, but that it is not possible to predict how variables influence an outcome across all generalised cases. Instead, the power of a variable is attached to a number of contextual conditions, some of which are unknown, thereby undermining Yin's replication logic (Yin, 2014).

In this study, using multiple cases facilitated consideration of how, or under which conditions, a variable such as social deprivation influenced access to hospice care. Any subsequent theoretical statements derived from a multiple site case study of this kind are about understanding how conditions may alter access to hospice care for populations in socially deprived areas. Attention was given to reoccurring conditions relevant across cases but arguments stopped short of making conclusive statements general to all contexts. This was in keeping with the philosophical stance underpinning this study, recognising that while an objective reality exists, our knowledge of that reality is fallible. To understand patterns that may

be reproducible across different cases, although not generalised across all cases, the conditions in which those patterns occur must be identified.

## 5.6. Methods

### 5.6.1. Selecting cases

As stated in one of the propositions, it was assumed at the outset of the study that the way hospice care is delivered has the potential to influence access in socially deprived areas. Therefore, the cases were sampled based on differences in the way hospice care was delivered. To aid with case selection, this study drew upon previous case study work conducted with these hospices, in which details about their model of care, including the types of services they delivered, was provided (Hasselaar and Payne, 2016). Three cases were considered sufficient for comparing different approaches to delivering hospice care, with the amount of data required for four or more cases likely to be so large it would hinder an in-depth and comprehensive comparison of findings. Table 8 outlines the inclusion and exclusion criteria for cases. As indicated in Table 8, one of the inclusion criteria was that cases included areas within the 10% most and least deprived areas nationally. While national deprivation rankings were used to sample cases, a decision was made later on to switch to a regional measure of relative deprivation when conducting the analysis. Details of this are provided later on in this chapter. Table 9 provides a short description and explanation of why each case was sampled.

Table 8: Case inclusion and exclusion criteria

	Case #1	Additional cases
Inclusion criteria	Contains areas that fall within the 10% most deprived and 10% least deprived nationally. Has a specific catchment area where services are delivered. Only one specialist palliative care provider offering services within the majority of that catchment area.	Same inclusion criteria PLUS: Offers different types of services or delivers them in a different way.
Exclusion criteria	An unspecified catchment area or a significant overlap of populations shared with another service provider.	Same exclusion criteria PLUS: No obvious differences in the type of services provided or how they are delivered.

**Table 9: Case descriptions and reason for sampling**

Case #1	Case #2	Case#3
Includes a hospice providing standard services (Inpatient, Hospice at Home, Day Hospice, Bereavement Services) provided by medium sized hospice (~£6m income, 120 staff, 500 volunteers).	Includes a hospice providing standard services plus hospital-based care and Clinical Nurse Specialist community team provided by large hospice (~£9m, 160 staff, 900 volunteers). Hospice also has close collaboration with heart failure clinical team.  Sampled due to hospital and community services, and those for non-cancer patients.	Includes a Hospice at Home/ Community service with no inpatient facilities provided by small hospice (~£1.1m, 70 staff, 200 volunteers). Clinical team based out of community hospital.  Sampled due to delivering only community services and no inpatient care.

### 5.6.2. Data collection

Two types of data were collected in each case study: archival data on hospice referrals and interview data. The main archival data in this study is the quantitative data relating to hospice referrals, collected from the participating hospice in each case. Data on area social deprivation were also collected, and associations between this variable and hospice referrals were examined. The qualitative data complemented and expanded on these findings by exploring the context in which referrals are generated and responded to. The study was designed so the quantitative data would be collected and analysed before qualitative data were collected. In practice, this occurred for the first two cases but not the third. When the work on the third case began, a complication with accessing the hospice records delayed the quantitative data collection by four months. To prevent further delays, the participants in that case were recruited and interviewed while a solution was found to the issue of the lack of access to the quantitative data. A three-month gap between the end of data collection in one case and the start of data collection in the next case ensured overlap was kept to a minimum.

#### 5.6.2.1. Archival records: Hospice referrals data

Data collected in a case study can include archival records such as service records, government-held population data, maps, and organisational records (Yin, 2018). Such data is usually quantitative and Yin (2018) suggests should be used in conjunction with other sources of information when producing and

analysing a case study. This study included data collected from archival records of three participating hospices. The data collected from the hospice referral records in each case included for all patients:

- Service(s) received
- Postcode
- Age/date-of-birth
- Sex/Gender
- Referrer
- Non-specific diagnosis (e.g. cancer)
- Date of referral
- Date of death
- Patient's GP practice

In each case, data were collected over a time period specific to each case and the limitations of the records kept by each hospice. Data collected in Case 1 covered the time period September 2016 to September 2018. The Case 2 dataset covered the period April 2016 and April 2019 and in Case 3, April 2016 and November 2019. As each case was analysed individually, quantitative data from different hospices were not pooled.

To protect patient anonymity, each patient's home postcode was replaced with a small area geographical code provided by the Office for National Statistics. A free and publicly available online government website (Ministry of Housing, Communities and Local Government, 2019d) assigns every postcode in England to a small area identifier; these small areas are called Lower Layer Output Areas (LSOAs) and cover a population of approximately 1500 people. Each hospice patient for whom there was a postcode was linked using this online tool to a corresponding LSOA; their postcodes were then deleted, leaving only the LSOA identifier. This data linkage and replacement occurred on-site at the hospice after the dataset was retrieved from the records system. From a hospice computer, the study dataset (now without postcodes) was placed in a secure shared folder online environment accessed by logging into the Lancaster University server. In each case, a hospice data manager oversaw the process.

Each of the small area identifiers (LSOAs) has a deprivation score and unique deprivation rank assigned to it, provided by the publicly available Indices of Multiple Deprivation (IMD) database (Ministry of Housing, Communities and Local Government, 2019c). By matching the LSOA identifiers in the study datasets to this publicly available IMD database, each area relevant to case was assigned a deprivation

rank and score. More detail on the IMD is provided in the section below discussing the quantitative analysis methods.

#### 5.6.2.2. Qualitative interviews

In each case, qualitative data were collected through interviews with healthcare professionals working for a hospice organisation (hospice staff) or in services that could refer patients to the hospice (referrers). In semi-structured interviews, all participants were invited to discuss their experiences and observations of caring for patients in socially deprived areas and, if relevant, referring patients to local hospice care. The interview length ranged from 20 mins to one hour.

When designing the study, I had initially planned to also interview patients, or their families, living in socially deprived areas who had both been referred or not been referred to the hospice. When collecting data for Case 1, considerable effort was made to recruit from this participant group. These efforts included recruiting through local charity and community networks, placing adverts around the hospice, and recruiting through hospice staff working in socially deprived areas. Despite these efforts, no patient or family member was successfully recruited. A small number of people who had expressed an interest in participating to hospice staff unfortunately died before being able to. Following these difficulties in recruiting patients or family members in the first case, no further efforts were made to recruit from this group in the subsequent cases, with the decision to instead focus on the perspective of healthcare professionals.

#### *Participant sampling*

Hospice staff were eligible if they were involved in the delivery or design of services, such as senior clinicians, frontline staff, and senior management team. Referrers were eligible if they could refer patients to hospice care and had been qualified for at least twelve months, increasing the likelihood they understood the best practice of hospice referrals.

Participants were sampled using purposive and snowballing sampling methods (Robson, 2016). Interviews were sought with specific healthcare professionals (purposive), and some participants were asked to identify other potential interviewees (snowballing).

**Table 10: Participant inclusion and exclusion criteria**

	<b>Participants</b>	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Hospice staff</b>	Hospice managers Service managers Service clinical staff Other relevant staff as identified by participants	Employed by service/hospice. Involved in the delivery or design of services.	Not employed directly by either the hospice or service.
<b>Referrers</b>	GPs District nurses Specialist nurses Specialist doctors	Able to refer to hospice care. Has been qualified for at least 12 months.	-

#### *Recruitment*

Participant recruitment was undertaken in one case at a time, allowing sufficient time for the interviews to be carried out and an initial analysis begun before recruitment began in the subsequent cases. This was to reduce the risk of interview data in one case influencing the analysis in the previous case.

#### **Hospice staff**

After the hospice management in each case confirmed the organisation's participation in the study prior to data collection, initial interviews took place with those in managerial roles in the hospice. In all cases, hospice staff who had already been in contact with the researcher to agree to the study taking place were invited to take part as the initial participants in each case. Subsequent participants from the hospice were identified through snowball sampling, where existing participants identify and contact other potential participants (Robson, 2016).

#### **Referrers**

Referrers were invited to participate by hospice staff or by the researcher directly, using contact information held by the hospice or in the public domain. Participants were also invited to contact me

themselves in news stories included in clinical locality newsletters, although in practice no participant said they reached out to me after seeing these stories. Most were contacted using contact details in the public domain, through snowball sampling or via the hospice and other non-NHS sites.

#### *Information sent to participants*

All potential participants received a participant information sheet and a consent form either in the post or by email, along with a written invitation to take part in the study. Those people who did not immediately respond to the initial invitation were sent a reminder after five days and, if required, a second reminder was sent after a further five days. All participants who expressed an interest were provided an opportunity to discuss any questions or concerns before scheduling the interview, although none did. The consent form was signed immediately prior to commencing the interview.

#### *Conducting the interviews*

Just over half the interviews were in person, either in the participant's home or place of work, and the rest took place over the phone. Face-to-face interviews are typically seen as preferable as a method of qualitative data collection, because they are seen as better at collecting the rich and descriptive data necessary for most qualitative analyses (Novick, 2008). However, in this study, telephone interviews were necessary in many instances and the use of this method likely helped to recruit higher numbers of participants. This is because the participants were healthcare professionals who, on the most part, had limited time and worked in settings where it would be difficult to book a private room ahead of time. For example, interviews conducted with hospital-based staff sometimes required me to contact the participant via the switchboard and wait on the phone until they were available.

Conducting both telephone and face-to-face interviews revealed the strengths and limitations of both approaches, reflecting findings in other studies. It was sometimes difficult to build rapport with participants over the phone, particularly when they were busy, whereas this rarely was an issue with the face-to-face interview participants. However, those conducted over the telephone were also more private, and potentially helped participants to speak openly about their experiences in a way that may not be as easy in person (Sturges and Hanrahan, 2004). When conducting telephone interviews in this study, I

employed strategies to help build rapport with participants that have been evidenced in other literature on telephone interviews. This included, for example, using more orientating statements for some questions (e.g. ‘this may sound like a strange question...’ or ‘let me know if you don’t understand what I’m asking’) or more validating statements and expressions of appreciation and reassurance (e.g. ‘thanks again for finding the time’ or ‘no, please continue, this is all really relevant’) (Drabble et al., 2016). Upon reflection, these strategies appear to reflect attempts to replace the non-verbal cues used to improve communication and facilitate rapport in face-to-face interviews. It is difficult to say whether these strategies worked. While it is feasible that richer data were obtained in the face-to-face interviews, data from all interviews contributed to the analysis in every case. Regardless, it would have been impossible to conduct many of the interviews without the option of a telephone call, meaning they were necessary for this study.

Having several pre-prepared questions and a topic guide anchored the interviews around key areas of interest, which was particularly useful in cases where healthcare professionals had limited time. Additionally, although the quantitative and qualitative data were collected separately, the findings of the hospice analysis led to some lines of enquiry explored in interviews. In Case 2, for example, the number of referrals through the local hospital led to a specific question being asked of participants to gather data on the working relationship between the hospital and the hospice staff. However, on the most part, the initial questions were broad and open-ended to allow participants to raise unanticipated points, as is the technique used in much qualitative research (Mabry, 2012).

### **Hospice staff**

Interviews with hospice staff covered hospice policy, relationships with referrers, the experiencing of receiving referrals, caring for patients in socially deprived areas, and perspectives on different patients’ needs, and the needs of the local area.

### **Referrers**

Interviews with referrers covered their experience of caring for patients from deprived areas, perspectives on different patients' needs, interactions with patients, decisions to refer, and understanding of the role of the local hospice.

### **5.6.3. Ethical considerations**

The processes described above concerning the collection of patient data, obtaining consent, and carrying out interviews were designed and followed in accordance to the recommendations from an NHS Research committee and in line with GDPR regulations (Data Protection Act 2018).

Additionally, the nature of the study called for reflection on several points related to research ethics. Firstly, the risk to participant anonymity; and secondly, the risk to patient identification were identifiable information discussed during interviews to be shared as part of the analysis, such as describing a patient with a rare condition or who lives in very unusual circumstances. Regarding the first, participants were told that, in addition to their own anonymity, the local area and the hospice would not be named in the study but that readers may still be able correctly guess the area or organisation from the description of the case. Because of this, and because many participants had a unique and distinctive job titles, broad job titles were used in place of actual titles. In a small number of interviews, participants raised this and specified how they would like to be referred to. The second point related to protecting the confidentiality of patients about whom participants talked in interviews. Concern about this was also raised in a small number of interviews. All participants were informed prior to taking part that information they shared was confidential but may be quoted or pooled with others' responses. When discussing individual patient cases, some participants became concerned that because of the uniqueness of the situation they were describing, there was a risk that the patient could be identified were that story to be shared. When this arose, I discussed the concern with the participant and clarified that situations where it may be possible for others to identify the patient or family would not be explicitly referenced in the study.

A third ethical consideration was around the use of hospice patient's postcode. While postcodes on their own may not always be considered identifiable data, when combined with other information they can become so (Information Commissioner's Offfce, 2018). In this study, the postcode was combined with other data, including diagnosis, gender, and age. This raised an issue, as it feasibly would have been

possible to identify a patient just by looking at these data in the hospice records system. To overcome this, the data extraction was led by an employee of the hospice in each case, who used their own login details to access the records and export the relevant data, with guidance from myself as the researcher. The postcodes were then linked with LSOA codes (see section above) on-site at the hospice before being deleted from the dataset. This prevented any further concerns associated with holding a potentially identifiable dataset on Lancaster University's servers.

## 5.7. Analysis

A multiple case study analysis comprises of two overarching analytical phases: the analysis of each individual case and the subsequent cross-case synthesis (Yin, 2014). In this thesis, these phases are referred to as the within-case analysis and the cross-case analysis, respectively. The within-case analysis concerned the study of the relationship between hospice referrals and social deprivation within each individual case. This phase derived findings from an analysis of hospice archival data (patient referral records) and of interview data with healthcare professionals. From this, a case summary was generated. After this was completed in each case, a cross-case analysis was undertaken. This is where the within-case findings were compared and contrasted; the intent (in this study) was to identify any repeated patterns and contextual conditions influencing hospice referrals within socially deprived areas. While there is some guidance on the how data might be organised to facilitate a cross-case analysis (Miles and Huberman, 1994, Stake, 2006), the actual process of interpreting and deriving cross-case themes is harder to discern. As described below, the cross-case analysis in this study drew upon methods of pattern matching and thematic analysis to derive cross-case themes from the data. Before outlining these methods, the following section describes the quantitative and qualitative components to the within-case analyses.

### 5.7.1. Within-case analysis

Each within-case analysis comprised of two parts. First, a quantitative statistical analysis of specific key data collected from hospice electronic records (identified a priori for the purpose of the study) explored the association between area deprivation, hospice referrals and different patient or provider

characteristics. This was followed by a qualitative analysis of data collected in participant interviews. On several occasions these analyses overlapped chronologically, particularly when findings of the qualitative analysis led to an additional analysis of the quantitative data. For example, in Case 2 the suggestion that patients in socially deprived areas may be referred to hospice care closer in time to their death than those living in more affluent areas led to an analysis of the patient data to quantify time spent as a hospice patient in all cases. A greater deal of overlap occurred between the quantitative and qualitative data analysis in Case 1 than the other cases, as the statistical model was adapted for several months after the first quantitative dataset was collected. By the time Case 3 began, no further changes to the statistical model were made. The following sections outline each phase of the within-case analysis, including the aims, summary and analytical methods.

### **5.7.2. Quantitative analysis**

#### **5.7.2.1. Aim of the within-case quantitative analysis**

The first step to understanding access to hospice care in socially deprived areas was to understand any differences in hospice referrals between areas of deprivation. The analysis of referrals in each case measured the extent to which hospice referrals varied between different areas of deprivation, once other confounding factors had been adjusted for. Further quantitative analyses explored the relationship between the characteristics of hospice patients - including who referred them, which service they received, and how late they were referred - and the deprivation of the area where they lived.

#### **5.7.2.2. Summary of approach**

Within each case, data about hospice patients were analysed in three analyses. The first analysis compared patient referrals across different areas of deprivation within the hospice's catchment area. Only the initial referral for each patient was used, meaning the analysis was of patients referred rather than total number of referrals; for simplicity, however, 'referrals' is used in this section as shorthand for 'patients referred'. A catchment area specified by the hospice provided the geographical boundaries to each case. The hospice catchment area was divided into Lower Layer Super Output Areas, or LSOAs, which already have a pre-specified boundary and an area deprivation value associated to them (at least

half the LSOA had to be within the hospice catchment area to be included). Each LSOA has a population of approximately 1500 people. Using the postcode from each patient's address, referrals were counted in each LSOA that fell within the hospice's catchment area. The association between referrals and LSOA area deprivation was measured using a mixed model Poisson regression analysis and adjusted for mortality, population age structure, population gender structure, population ethnicity structure, distance to main hospice building, and whether an area was urban or rural (Table 11).

The first analysis compared referrals in different LSOAs within the hospice's catchment area in that case, including areas where there were no or low referrals. The second and third analysis only included data from patients who were referred to the hospice. In the second, patients living in different areas of deprivation were compared to see if they differed in the initial service they were referred to, the types of healthcare professionals who referred them, and in diagnosis, gender, and age. The third analysis looked at the association between patient area deprivation and late referral to hospice.

#### 5.7.2.3. Analysis 1: Hospice referral rates

Research question: What is the association between area deprivation and receipt of hospice care?

The purpose of analysing hospice referrals at a population level was to understand the association between area deprivation and hospice referrals within each case. Each analysis included several variables other than area deprivation that might have explained the association of some areas with higher or lower numbers of referrals. Table 11 outlines each variable included in the model, the reason for their inclusion, the format in which they are included, and the source of those data.

#### *Measuring hospice referrals*

After the patient data were collected and each postcode linked to a corresponding LSOA, the number of occurrences of every case-specific LSOA in that dataset was counted. Because the dataset was of unique individual patients, rather than care episodes, each patient was only counted once. The number of times an LSOA appears in this dataset is the referral count. This data column was then attached to the dataset of other LSOA-level variables, described below.

### *Measuring area deprivation*

The study used a measure of area deprivation provided by the national 2015 Index of Multiple Deprivation (IMD). The IMD is a composite measure of area deprivation that brings together dozens of different measures related to seven domains of deprivation: income, employment, education, health and disability, barriers to housing and services, living environment, and crime. Every LSOA in England has a score for each of these domains, which are then combined and weighted in the IMD with income and employment scores contributing the most. These IMD scores are then ranked from one to 32,844, with the lowest rank being the most deprived area and the highest the least deprived area nationally.

The IMD is one of several measures of social deprivation available in England. Others include the Carstairs Index (Carstairs, 1995), Townsend Deprivation Index (Townsend et al., 1988), and the Jarman Deprivation Index (Jarman, 1983). Where the IMD differs to the others is in comprehensiveness. For example, the Carstairs Index and Townsend Index both collate just four indicators based on census data. The Jarman Index includes more indicators but was designed to capture differences in workload of GP practices and thus is built to capture need for primary care rather than a holistic depiction of social deprivation (Jarman, 1983). In contrast the IMD has seven domains of deprivation, (income, employment, education, crime, environment, access to services, and health) with numerous indicators contributing to each of those domains. While this is arguably less focused, it provides a much more holistic and thorough depiction of social deprivation. Importantly, the IMD is constructed using administrative data and updated every four years, and does not suffer from a ten-year data lag which is a limitation of indices based on census data.

Table 11: Variables included in hospice referral rates analysis

Variable	Reason for inclusion	Format	Source of data
Hospice referrals	Main outcome of interest	Number of hospice referrals per LSOA (discrete)	Hospice in case
Area Deprivation	Main explanatory variable of interest	Regional deprivation quintiles calculated from on the national 2015 Index of Multiple Deprivation (IMD) rank. Deprivation computed into a binary categorical variable comparing the 20 most deprived areas to all other areas.	Department for Communities, UK government
Area Rurality	Rurality a barrier to hospice referral and access to other end-of-life care (Evans et al., 2003).	LSOA Rural/Urban Classification	Office for National Statistics
Area Mortality	Mortality is used as a crude measure of need for specialist palliative care (Etkind et al., 2017)	LSOA crude mortality rate	Office for National Statistics
Population age structure	Older age believed to be a barrier to hospice referral (Burt and Raine, 2006)	Proportion of LSOA adult (+18) population aged over 65	Office for National Statistics
Population ethnicity structure	Non-white ethnicity believed to be a barrier to hospice referral (Evans et al., 2011)	Proportion of LSOA adult (+18) population who are white	Office for National Statistics
Population gender structure	Gender influences end-of-life care experiences (Gott et al., 2020, Morgan et al., 2016) and care received at the end of life (Miesfeldt et al., 2012)	Proportion of LSOA adult (+18) population who are female	Office for National Statistics
Distance	Referrals assumed to decrease with increasing distance from the hospice	Distance (km) from main hospice building (using LSOA centroid and polygon data)	Office for National Statistics (for LSOA centroid and polygon data)

This study took an innovative approach to using the LSOA rankings provided by the Index of Multiple Deprivation. Instead of using the national ranks provided by the IMD, which rank LSOAs from 1 (most deprived) to 32,844 (least deprived) by comparing areas nationally, this study ranked areas in relation to others within the catchment area of each case. These so-called regional ranks are more appropriate for a study using case study methods, where understanding about the case should be driven primarily by data from within the case (Yin, 2014). A case study approach also requires understanding about the context particular to an individual case (Simons, 2009). It would be inappropriate, therefore, to use IMD rankings of areas from outside a case to explore deprivation within a case. Consequently, each within-case analysis was designed to capture the variation of area deprivation within each case, rather than compare it to national deprivation ranks. This decision was made following multiple discussions with statisticians and case study methodologists about the appropriate use of this data.

Regional IMD rankings were computed for LSOAs in each case by re-ranking the original national IMD rankings assigned to LSOAs. In Case 1, for example, there were 157 LSOAs with national IMD ranks ranging between 80 and 32,800. These were changed to ranks one to 157, where one was the most deprived area in that case and 157 the least deprived area. From these regional rankings, regional quintiles were computed, where quintile 1 is the 20% most deprived areas and quintile 5 is 20% least deprived areas in each case.

#### 5.7.2.4. Adjusting for need and other factors

An analysis of referrals to hospice care has to consider potential differences in need for a referral, as well as factors additional to area deprivation that could influence referrals. To estimate need, the study drew on measures of palliative care need at a population level based on mortality (Etkind et al., 2017, Rosenwax et al., 2005). This study used a percentage (69%) of all-cause mortality as a crude estimate of the proportion of the population likely to benefit from hospice care, based on the lowest estimate of palliative care need in high-income countries calculated by Murtagh et al. (2013). This is a blunt measure, which did not account for complex psychological, social, spiritual or physical symptoms that may contribute to need for hospice care. Given the likelihood that patients in this study were referred to hospice care in the last year of life, however, annual population mortality data is arguably a sufficient estimate of the number of people who could have benefitted from a referral. A lengthier discussion on

the limitations of adjusting for complex palliative care needs at a population level is included in Chapter 8.

In addition to mortality, a number of other population-level characteristics were adjusted for in each analysis of hospice referrals; the reasons for including these variables are provided in Table 11. Broadly, studies looking at barriers to accessing hospice care have found that patients from ethnic minority populations, those who live in rural communities, and those who are older have a lower likelihood of referrals (Burt and Raine, 2006; Evans et al., 2011; Evans et al., 2003). There is also evidence that women tend to take on responsibility for caregiving at the end-of-life and are less likely than men to rely on formal care services (Williams et al., 2017, Morgan et al., 2016) consequently, hospice referrals may be associated with gender. Population measures of each of these characteristics were included in the model; details are provided in Table 11.

#### *All-cause mortality vs cause-specific mortality*

Having a non-cancer condition is associated with both social deprivation (ONS, 2017) and with difficulties receiving a hospice referral (Ahmed et al., 2004, Andrews and Seymour, 2011). Consequently, it was of interest to explore how LSOA mortality rates specific to different causes of death may alter the relationship between area social deprivation and hospice referrals. To do this, sensitive and confidential cause-specific death registration data were requested from the Office for National Statistics (ONS). After obtaining approval from the ONS, I accessed the death registration data from an ONS Secure Research Site and calculated age-adjusted cause-specific mortality rates for all LSOAs in England, which were approved for release by the ONS. However, it subsequently became apparent that crude mortality was a preferable variable than age-adjusted mortality (because the analysis already adjusted for age by including a specific variable for population age structure). For data confidentiality reasons, it was not possible to export crude mortality rates from the ONS Secure Research Site. I had planned to re-run the analysis from within the Secure Research Site in 2020 and then export results of these analyses for each of the three cases. This was not possible because of restrictions related to the COVID-19 pandemic. Consequently, the final model in this analysis does not include cause-specific crude mortality rates. Instead, the final model used crude mortality rate calculated from publicly available death and population data, rather than from sensitive and confidential data held by the ONS.

#### 5.7.2.5. Reporting of descriptive data relating to case catchment area characteristics

Descriptive statistics for the data relevant to Analysis 1 are reported in the Chapter 6 (results of within-case analysis) and in Appendix E. This includes average (mean) percentage of LSOA populations that fall into different variable characteristics, for example the mean percentage of LSOAs classed as 'rural' and the mean percentage of populations aged over 65 in LSOAs within the catchment area of that case. Chapter 6 also presents the distribution of area characteristics by regional deprivation quintile, for each case.

#### 5.7.2.6. Statistical analysis of referral rates

This analysis used a Poisson regression random effects model to model the association between area social deprivation and hospice referrals in each case.

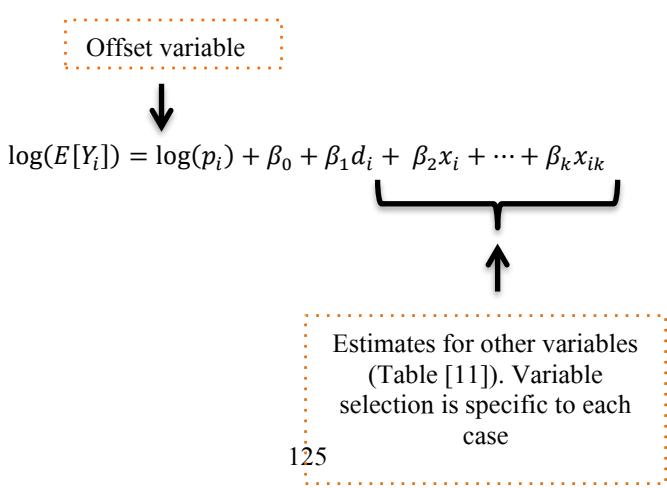
The outcome of this analysis is hospice referral. Hospice referral is a discrete count variable that cannot take a negative value (it is impossible for an area to have a negative referral) and has to be an integer (it is impossible to have 1.5 referrals, for example). Additionally, this study is interested in initial referrals, meaning the possible number of referrals is limited (in this instance) by the size of the adult population in an area. Hospice referrals are an example of count data, then, that is likely to follow a Poisson distribution.

Named after French mathematician Simeon Poisson who first described it, a Poisson distribution describes the distribution of discrete data for cases where there are many opportunities for an event to occur but the chance of an event occurring is low (Riffenburgh, 2012). Applied to hospice referrals, the opportunity for a hospice referral in a given LSOA area (and within a specific time period) relates to the number of people who could potentially be referred. This is the adult population of an LSOA, which is approximately 1500 people. However, it is highly likely that the chance of a referral occurring is low, because of the requirement for a person to have an advanced illness that requires palliative or end-of-life care input. The actual distribution of hospice referrals data in each case is shown in Appendix E, confirming that the data follow a Poisson distribution as indicated by a high number of low counts (this can also be described as a positively skewed data).

It is not possible to analyse data following a Poisson distribution using linear regression, which assumes the outcomes can have infinite values. Instead, a Poisson regression model, a case of generalised linear regression, can model count data that follows a Poisson distribution (Cameron and Trivedi, 1998). A Poisson regression overcomes the non-linearity of the outcome distribution by using a natural log link function. Taking the natural log of the count variable allows the relationships between the count variable and the explanatory variables to be described in linear terms. This produces estimates on the log scale. Taking the exponentiate of the estimates produces a rate ratio, which in this study reflects the change in hospice referrals corresponding to a one-unit change in the explanatory variable.

Another feature of a Poisson regression model is the offset, which captures the finite number of opportunities for the outcome to occur. When count data are presented in the form of a rate, the offset is the denominator and the count is the numerator. In this study, the offset is adult population in each LSOA, and the count is the number of hospice referrals in that LSOA. Along with the outcome variable, the offset is also transformed on the log scale.

The associations between area characteristics and hospice referrals were explored in univariate Poisson regression models, before using stepwise regression to select the variables for the multivariate model. The formula below describes a general version of the multivariate Poisson regression formula used in Analysis 1 of each case, where  $Y_i$  is number of hospice referrals in the  $i^{th}$  LSOA,  $p$  is the adult population (the offset), and  $d$  indicates whether the LSOA is in the 20% most deprived quintile or not. Not every variable is specified in this general formula because different variables are included in each within-case analysis following the stepwise regression process.



### *Overdispersion in Poisson loglinear models*

An assumption of the Poisson model is that mean is equal to variance. However, this theoretical assumption usually does not hold with ‘real world’ data, where empirical variance is often greater than the mean (Cameron and Trivedi, 1998). This creates overdispersion in the model, reducing the accuracy of the model estimates and of the model overall. Because it is related to the variance, one way to overcome overdispersion is to include data for whatever variable is contributing to that variance. Practically, this can be difficult if data are not available or the variable is unknown. This was the case in this study, with some unknown factors not captured in the model likely influencing referrals. This meant a statistical solution to overdispersion was required.

A random effect component was added to this model to address this issue. Random effects models are underpinned by the assumption that there is a ‘natural’ variance between subjects (in this study, LSOAs) that is reflected in the differences in their associated coefficients (Diggle et al., 2013). This variance reflects some characteristic of the subject that is not already captured in the variables already specified in the model. In this study, it was assumed that there was additional unknown variability associated with the small areas (LSOA) within which referrals were counted, and that this contributed to overdispersion. To address this, LSOA was included as a random effect,  $U_i$  in the formula below. Here  $U_i$  represents the heterogeneity across LSOAs, recognising that patients referred from the same LSOA are likely to share a characteristic not already captured in the model.

$$\log(E[Y_i | U_i]) = \log(P_i) + \beta_0 + \beta_1 d_{i1} + \beta_2 x_i + \cdots + \beta_k x_{ik} + U_i$$

In each case, a stepwise regression was used to select the best fitting model before adding LSOA ID as a random effect. The fit of the regression models with and without the random effect were compared using an Analysis of Variance (ANOVA) test, to examine whether the more complicated random effects model statistically significantly reduced the residual deviance (and thus was a better fit).

#### 5.7.2.7. Summary of statistical steps for Analysis 1 (hospice referral rates)

- Descriptive statistics of hospice referral distribution, area characteristics, and the distribution of referrals and area characteristics by regional deprivation quintile
- Perform univariate Poisson regression models for each area characteristics and hospice referrals.
- Select multivariate fixed effects Poisson regression model using stepwise regression and test for overdispersion.
- Include random effect at LSOA level to run multivariate random effects Poisson regression model.
- The fixed effects and random effects models are compared using plots of predicted versus expected values and ANOVA tests.

#### 5.7.2.8. Analysis 2: Hospice patient characteristics

##### **Research questions:**

- 1) Which referrers/services are more likely to refer/receive patients from more deprived areas?
- 2) What is the association between the deprivation of the area where patients live and their diagnosis, age, and gender?

The aim of the analysis of individual hospice patient data was to understand the association between the deprivation of the area where a hospice patient lives and other patient characteristics. Table 12 describes each variable included in the model and, where applicable, the different factor levels.

**Table 12: Variables in patient characteristics analysis**

Variable	Description	Levels
Area deprivation rank (outcome)	Discrete variable (treated as continuous); LSOA regional deprivation rank	N/A
Initial referrer	Multi-level factor; The healthcare provider recorded as the first referrer of patient	GP District Nurse Hospital Other

Initial service received	Multi-level factor; The initial hospice service received by a patient	Hospice at Home Inpatient Unit (if applicable) Day Unit (if applicable) Community (if applicable) Hospital (if applicable)
Diagnosis	Binary factor; A patient's primary high-level diagnosis	Cancer (0) Non-cancer (1)
Gender	Binary factor; Patient's gender	Female (0) Male (1)
Age	Discrete variable (treated as continuous); Patients age at time of referral	N/A

#### 5.7.2.9. Reporting of descriptive data relating to patient characteristics

Descriptive data relating to the analysis of patient characteristics are included in tables presented in Appendix E. This includes tables reporting the distribution of patients across each variable (e.g. the numbers of patients referred by GP surgeries). The mean, median, and interquartile range of regional deprivation rank distributed across different patient characteristics are also reported in Appendix F.

#### 5.7.2.10. Missing data

This analysis used routine data about hospice patients collected by hospice staff as part of normal clinical care and entered into the hospice records. While a strength of this is that the data reflects real world practices, it suffered from the same vulnerabilities as many other studies of routine data. This includes the potential for poor data quality, including missing data or data inappropriate for answering the proposed research question (Davies et al., 2016). Appendix I includes tables indicating the number and proportion of missing data for explanatory variables included in patient characteristics analysis in each case; no data were missing for the dependent outcome variable (deprivation rank) for patients in all cases. Further details about missing data are provided in Chapter 7, the implications of this for interpreting study findings are discussed in Chapter 8 (discussion chapter).

##### 5.7.2.11. Statistical methods of patient characteristics analysis

The data in the variables listed in Table 12 were input into a multiple linear regression. Multiple linear regression is a form of regression that models a linear relationship between multiple explanatory variables and the outcome of interest, where the outcome is a numerical (continuous) variable (Kirkwood and Sterne, 2003). It is appropriate for the analysis of patient characteristics, where the outcome of interest is the regional deprivation rank. While area deprivation rank is technically a discrete variable that can only take whole integers, the large number of ranks (Case 1 = 156, Case 2 = 206, Case 3 = 92) means it is justifiable to treat it as a continuous variable. While it is unusual to specify area deprivation as the ‘outcome’, here it was appropriate to do so because of the interest in how area deprivation is distributed within each referrer or service category rather than the other way around. That allowed for easier comparison of the deprivation of areas where patients lived between different types of referrers and services.

Separate models were run to analyse the relationship of social deprivation with (1) referrer group and (2) type of service received. This is because who referred patients and which service patients received were considered as separate parts of the process of being referred. In discussions with hospice staff it was suggested that in many cases, a patient would simply be referred to hospice care and hospice staff would be responsible for deciding which hospice service was appropriate for that patient. Therefore, even if referrer group and service received had a statistical association, it would be very difficult to interpret what that meant in practice – and potentially meaningless - without knowing who were deciding which service a patient should receive. Therefore, it was decided that conceptually it was not appropriate to include them in the same analysis.

The formula for this analysis is described below, where  $Y_i$  is the regional area deprivation rank for the  $i^{th}$  patient,  $r$  is the referrer group,  $s$  the initial service received,  $d$  is the diagnosis,  $a$  is age and  $g$  is gender.

Diagnosis, age, and gender were included in the model if found to have a statistically significant ( $p < 0.05$ ) association with deprivation rank in univariate analysis. Stepwise regression was not used because of the

low number of variables under consideration. Case 3 excluded service as an independent factor (because there is only one hospice service for patients in that case).

The formula for the analysis of referrer group:

$$Y_i = \beta_0 + \beta_1 r_i + \beta_3 d_i + \beta_4 a_i + \beta_5 g_i$$

The formula for the analysis of service received:

$$Y_i = \beta_0 + \beta_2 s_i + \beta_3 d_i + \beta_4 a_i + \beta_5 g_i$$

#### 5.7.2.12. Analysis 3: Late Referrals

Research question: What is the association between the deprivation of an area where a patient lives and how late they are referred to hospice care?

The aim of the late referrals analysis (Analysis 3) was to understand whether patients in more deprived areas were any more or less likely to be referred late to hospice care than those in less deprived areas. Although not included in the original research proposal, this question emerged whilst conducting qualitative interviews in Case 2. Given the study's focus on the initial contact between patients and hospice care, it became clear that it would be useful to understand how close that contact was to the patient's death. The analysis of late referrals and area deprivation was adjusted for patient diagnosis, age, and gender (Table 13).

An approach adopted from Allsop et al. (2018) was used to analyse late referrals using routine data. In each case, all hospice patients for whom a date of death was recorded were included in this analysis. The length of time between their initial referral to hospice care and their death was calculated, with a specified length of time used as a threshold for defining 'late' referrals. Initially, an initial referral <30 days before death was chosen, in line with the approach taken by Allsop et al. (2018). The authors of that study had chosen a threshold of 30 days to indicate late referral, citing evidence that a referral to palliative four weeks before death reduces the likelihood of emergency hospital admissions and increased access to an opioid (Ziegler et al., 2018). In this study, however, the median length of time between referral and death for all hospice patients in each case was below 30 days (ranging from 8-24 days before death), compared

to 48 days national average identified by Allsop et al. (2018). In light of this, multiple thresholds for defining late referrals were used in this study:

- 1) Late referrals defined as patients referred  $\leq$  30 days before death, a threshold used by Allsop et al. (2018).
- 2) Late referrals defined as patients referred  $\leq$  14 days before death, to capture any differences in very late referrals by area social deprivation.
- 3) Late referrals defined by the median length of time receiving hospice care for all patients in that case.

**Table 13: Variables included in the late referrals analysis**

Variable	Description	Levels
Late referral (outcome)	A binary outcome variable.	Yes / No
Area deprivation quintile	Case-specific area deprivation quintiles calculated from the Index of Multiple Deprivation (IMD) ranks	Five levels (1 – most deprived; 5 – least deprived)
Diagnosis	Binary factor; A patient's primary high-level diagnosis	Cancer (0) Non-cancer (1)
Gender	Binary factor; Patient's gender	Female (0) Male (1)
Age	Discrete variable (treated as continuous); Patients age at time of referral	N/A

#### 5.7.2.13. Reporting of descriptive statistics

Summary statistics (mean, median, min, max, and IQR) for the length of time patients received hospice care are provided in Appendix G, with brief summary of findings discussed in each case. Summary statistics (mean, median, and IQR) are also reported by different patient characteristics.

In this analysis, deprivation is used as an explanatory (independent) variable. For this reason, I return to using deprivation quintile as the measure of deprivation, rather than deprivation rank, which was used in Analysis 2 where deprivation was the outcome variable. This is because of the ease of interpreting effects associated with quintiles (dichotomised into most deprived 20% or not) when used as an explanatory variable.

#### 5.7.2.14. Statistical methods of late referrals

Multiple logistic regression was used to investigate the association between other patient characteristics and likelihood to be referred later. Logistic regression was used because late referrals is a binary categorical outcome (yes/no). As with Poisson regression, logistic regression is a case of generalised linear regression and is related to the explanatory variables by a link function (Kirkwood and Sterne, 2003). Transforming the outcome variable using the logit (log odds) function, a logistic regression produces log odds, which can be transformed into odds ratios (Kirkwood and Sterne, 2003). The formula for a multiple logistic regression looks similar to that for a multiple linear regression, but taking the log odds of the outcome. This is expressed in the following formula, where  $P$  represents the probability of a late referral to hospice care for the  $i^{th}$  patient,  $d$  indicates whether that patient lives in the 20% most deprived area,  $c$  is the diagnosis,  $a$  is age and  $g$  is gender.

$$\text{Log} \left( \frac{P_i}{1 - P_i} \right) = \beta_0 + \beta_1 d_1 + \beta_2 c + \beta_3 a + \beta_4 g$$

### 5.7.3. Qualitative analysis

#### 5.7.3.1. Aim of the within-case qualitative analysis

The analysis of hospice referrals data in each case provided clarity about overall patterns of receiving care but raised further questions about what led to these population-level patterns. The exact nature of these questions varied between cases, as each case generated different findings from the referrals analysis. The purpose of the within-case qualitative analysis was to develop plausible explanations for referral patterns from the perspective of healthcare professionals who participated in the study, as well as explore more general experiences of providing end-of-life care in the context of social deprivation.

#### 5.7.3.2. Summary of the approach

In the qualitative within-case analysis, interviews with healthcare professionals were analysed using thematic analysis (Braun and Clarke, 2006). The approach to thematic analysis adopted in this study reflects the ontological and epistemological philosophy underpinning this research. Inductive coding of

the observations and experiences of professionals aided the development of themes regarding factors that influenced access to hospice care and hospice referrals in the context of social deprivation. Each theme is distinct but related to one another and, together, aim to summarise the phenomenon of providing hospice care in socially deprived areas in that case.

In taking a predominantly inductive approach to the within-case qualitative analysis, this stage of the analysis is similar to the general analytical strategy to case study analysis described by Yin (2018, p.169) as “working your data from the ‘ground up’”. While Yin (2018), referencing Miles and Huberman (1994) suggests some techniques to manipulate data into different displays, and then later suggests specific analytical strategies for drawing conclusions about the study, there is less guidance in case study texts on how to move between these stages. Thematic analysis offers more detailed guidance on the earlier stages of qualitative analysis and how to move between this and developing broader analytical findings. It is conducive with case study research, offering what Yin (2018) describes as a general analytical strategy with which to approach complex and detailed data.

#### 5.7.3.3. An overview of thematic analysis

Thematic analysis (Braun and Clarke, 2006, Braun and Clarke, 2012) was used in this study to explore, interpret, and summarise qualitative data. At its simplest, thematic analysis is a way to generate analytical themes from a qualitative data set (Braun and Clarke, 2012). Data are coded and these codes refined into broad themes. Themes are meaningful entities about the dataset as a whole, sometimes treated as real entities to be ‘discovered’ by the researcher and other times seen as constructed by the researcher to reflect their subjective interpretation of the data (Braun et al., 2016). The meaning of themes in this study is described in more detail below but, broadly, they are treated as descriptions of phenomena that occurred in each case, whilst recognising the limits of the data to reveal those phenomena and the role of the researcher in interpreting them.

A thematic analysis involves six key stages: familiarisation with the data, initial coding, developing themes, reviewing themes, summarising the themes, and finally writing up a report (Braun and Clarke, 2006). Researchers are not expected to follow these step by step; the experience is typically more fluid. Ultimately, however, the process begins with reading the data and ends with a summative interpretation

of what the data suggest. In defining six phases of analysis, thematic analysis provides an overarching structure or framework for approaching the within-case qualitative data analysis. As such, it can be used flexibly to fit different philosophical perspectives (Vaismoradi et al., 2013). How researchers using thematic analysis move between empirical evidence and theoretical ideas depends on their epistemological stance and the nature of the problem they are trying to solve.

#### 5.7.3.4. A reflexive approach to thematic analysis

Similar to a form of thematic analysis referred to as reflexive thematic analysis (Braun and Clarke, 2019), the particular approach used in this study reflects the philosophical position underpinning this research. The position subscribed to is that reality is pursuable because an objective reality exists, but knowledge of that reality is always fallible. This fallibility of knowledge provides space for an interpretative understanding of reality, with the caveat that this interpretation is an attempt to pursue something that is ‘true’ within the data, rather than a constructed reality itself. As such, the observations and experiences shared by participants in this study provided a view on the phenomenon of access to hospice care in socially deprived areas as it really occurred in each case. Semantic and inductive coding of data aided understanding of this, with initial codes closely reflecting the literal content of the data (Braun and Clarke, 2012). A more interpretative step followed using latent coding (where selected findings were re-coded based on my interpretation of the meaning of the data), with codes then refined and reduced into themes that reflected overall case findings on hospice referrals and providing end-of-life care in the context of social deprivation. Although falling within the remit of reflexive thematic analysis, the approach in this study was distinctive from a purely qualitative approach, what Braun and Clarke (2019, p.594) refer to as ‘Big Q’. Big Q is used to distinguish approaches to qualitative research that are embedded in qualitative paradigms and worldviews, in contrast to small q research which employs qualitative methods but from the philosophical perspective closer to a positivism, or something similar (Braun and Clarke, 2019). In this study, themes were developed using techniques that encouraged creativity and imaginative thinking (e.g. concept mapping) but with an intent to corroborate and triangulate evidence. This placed the within-case thematic development firmly in the domain of a mixed methods critical realist study (Creswell, 2009, Wynn and Williams, 2012).

#### *Positionality*

As well as reflecting on the philosophical beliefs underpinning the analytical approach, a reflexive approach to TA also involves reflecting on my position as the interviewer and the assumptions that I bring to the interview and analysis (Braun and Clarke, 2019).

The study was orientated around the topic of social deprivation and hospice care, particularly whether and how regular ‘everyday’ hospice care was reaching people in the most socially deprived areas. My approach to researching this topic was influenced by my ‘outsider’ status, as someone who was not clinically trained and with no experience working in health and social care settings. As such, I lacked experience or knowledge about hospice and other healthcare that a clinician might hold. A consequence of this was that part of the interviews involved clarification about the participants’ role and responsibilities in caring for patients at the end of life. While asking participants to explain basic aspects to their role was in some ways a disadvantage, largely because it took up time in the interview, there was also an advantage to being an ‘outsider’. Asking participants to explain everyday processes provided a useful springboard for thinking about how these processes may be affected by social deprivation.

Additionally, I came to this PhD having recently researched discrimination faced by dying prisoners experiencing extremely poor access to palliative care. This followed several years working as a journalist, including covering stories about discriminatory policies and practices effecting undocumented migrants, asylum seekers and refugees, LGBT communities, and other disadvantaged groups. A consequence of this was that I approached this PhD with an expectation of finding inequities in hospice referrals across socially deprived areas. Aware that I may unintentionally seek examples of inequity and ignore examples of equitable care provided by interview participants, I made notes following the interviews highlighting any surprising or unexpected findings, and took care to acknowledge and expand on these notes where relevant while coding the data.

#### 5.7.3.5. Applying the concepts of thematic analysis

In this section, I discuss the use of thematic analysis concepts in the within-case analysis, and the techniques employed to try to achieve analytical and epistemological coherence. The six stages of thematic analysis outlined by Braun and Clarke (2006; 2019) provided a structure for approaching the within-case analysis. The analytic concepts or techniques used in this within-case analysis are described

below. Reflecting the influence and role of the researcher in operationalising these techniques, first person tense is used to describe how concepts were applied.

### *Familiarisation*

To become ‘familiar’ with the data, I transcribed each interview and read the transcripts several times. During this process, I made notes on the points emphasised by the participant, any new considerations raised by them, as well as initial comparisons between that interview and previous ones. Writing post interview notes using the memo tool in the NVivo software enabled me to refer to these initial ideas later on in the analysis and track the process of the analysis.

### *Coding*

The approach taken to coding was what (Creswell, 2009, Wynn and Williams, 2012) describe as semantic and inductive. I read the interviews line-by-line and coded any statements relevant to accessing to hospice care semantically, meaning the codes reflected what the participant said rather than an interpretation of the participant’s meaning. I induced the codes and resulting coding structure from the data, rather than being driven by a priori codes developed from theory about accessing hospice care in socially deprived areas. Although Braun and Clarke (2006) suggest having the complete dataset before beginning coding, I chose to begin initial coding of each interview shortly after the interview had been transcribed. This was primarily because the interviews were spread out over long periods of time and waiting until all interviews were complete would have delayed analysis substantially.

After coding all interviews in each case, I categorised codes under broad domains of “referrer consultation” and “hospice providing care” to ease comparison of referrer and hospice staff’s perspectives on hospice referrals. Further coding categories of “triggering a hospice referral” and “context” helped to organise data related to more immediate factors influencing referrals of disadvantaged patients and those related to the contextual conditions of the case. This was in line with my approach to reflexive thematic analysis, which stemmed from a critical realism perspective. Consequently, I was interested in capturing observations about immediate factors influencing referrals and those about the underpinning conditions and context attached to referrals.

I slowly reformed and synthesised the initial codes through rereading of codes and data, particularly as the dataset grew. At this stage, I moved between semantic and latent coding as I reflected on the meaning behind participant's statements as well as their literal content. In this way, the coding stage of this thematic analysis overlapped with the early stages of theme development. The initial themes were identified during the process of re-coding and synthesising. The link between code reforming and theme developing is supported by (Braun et al., 2016, p.741) conceptualisation of coding, described as "a process of searching for evidence of identified themes". The final themes in each case were not categorised under the coding domains described above but rather described the evidence as a whole, synthesising the experiences of different healthcare professionals to get a broader understanding of factors influencing the referral of patients in socially deprived areas.

### *Themes*

Coding provides the foundation from which to build themes. Because themes are broad units of meaning identified and named by the researcher by distilling and organising codes, they are usually an abstract word or phrase that has not been explicitly stated by participants (Boyatzis, 1998). Instead, they are chosen by the researcher to reflect a broader idea or concept observed in the data (DeSantis and Ugarriza, 2000). In this study, I did not determine themes from how often a code or idea occurred in the data, but on how well I thought they captured what the data said.

### *Creating and validating themes*

The purpose of creating themes in each within-case analysis was to identify how factors influenced access, focusing on referrals as a key component to access, to hospice care in socially deprived areas in each case. To aid this, I drew on post-positivist techniques of corroborating and triangulating evidence to develop themes that were interpretative but rigorously interrogated to ensure they reflected, as far as possible, the phenomenon as it had occurred in that case. This is an example of how my approach to reflexive thematic analysis diverts considerably from the Big Q approaches used by proponents of this analytical approach (Braun and Clarke, 2019). Corroborating the developing themes by repeatedly checking their validity in the empirical evidence helps to strengthen the arguments explaining how factors influence access in each case. This is a method of sense-checking findings as they develop by confirming in the first instances that themes are appropriately described and, secondly, exploring the

strength of the explanations in comparison to other possible causes. It is an approach adapted from principles of case study research devised for critical realists, which suggests researchers can validate their findings by asking what would one expect to see in the data were the proposed explanation accurate (Wynn and Williams, 2012).

An additional method of increasing the validity of the findings is the use of triangulation (Creswell, 2009). A form of corroboration, triangulation of evidence from different data sources helps to reduce the influence of bias on the research and strengthen the plausibility of findings (Wynn and Williams, 2012). Often used within mixed methods research, triangulation can take different forms including the comparison of quantitative and qualitative results or the perspectives of different interview participants. I drew on triangulation methods when moving between the statistical findings from hospice referral records and the experiences of participants, as I tried to identify plausible explanations given findings from both of these sources.

The approach described above resulted in a separate coding tree for each case, reflecting the uniqueness of the within-case analyses. While some code names were the same, or similar, across the three cases, the codes were organised and interpreted into a different set of themes for each case. A different approach was taken for the cross-case analysis, as described below.

#### **5.7.4. Cross-case analysis**

##### **5.7.4.1. Aim of the cross-case analysis**

The purpose of the cross-case analysis was to generate an explanation as to how different factors influence access to hospice care for populations in socially deprived areas across the cases.

An additional aim was to use the cross-case comparison – and the unique context to each case – to explore how different contextual conditions facilitated or hindered referrals in socially deprived areas. In doing so, the cross-case analysis aims to strengthen understanding of the relationship between socioeconomic position (measured by social deprivation) and access to hospice care.

#### 5.7.4.2. Summary of approach

The approach to the cross-case analysis departed from the phases of thematic analysis used for the within-case analysis, although was similar in its inductive approach to generating themes and adherence to the principles of corroborating and triangulating evidence. Adapting pattern-matching techniques described by Yin (2018), the outcomes and explanatory findings from each case were mainly compared using matrices and visual concept mapping.

#### 5.7.4.3. Pattern matching

By comparing data across the three cases and considering what these cases suggest as a whole about accessing hospice care, I arrived at an understanding of the relationship between socioeconomic position and access to hospice care that could be generalised across these cases. The technique used was adapted from the pattern matching approach described by Yin (2018), building upon the work of (Trochim, 1989). In the form of pattern matching described by these authors, a priori theoretical predictions about the outcomes of phenomena are made and ‘tested’ by case data and the theory is either validated or debunked. The language of experimental logic in pattern matching methods reflects the post-positivist underpinnings of this technique.

This study uses pattern matching in the sense that the multiple outcomes (referral rates, referrals to different services, referrals of different diagnostic groups, etc.) were compared across cases, along with the circumstances and contextual conditions that appeared to influence these outcomes. The approach in this study taken departed from that proposed by Yin (2014) in that it did not start with theoretical predictions about the data. Instead the cross-case analysis was initially carried out inductively, consistent with the inductive approach taken in the within-case analyses. Through this inductive exploration of the similarities and differences between the cases, I generated cross-case themes that reflected a general explanation as to how different factors influenced access to hospice care for people in socially deprived areas in these cases. More attention was paid to building themes from empirical data rather than checking themes derived from theory against the data. As the themes began to take shape, it became apparent that some concepts drawn from the study’s theoretical framework were potentially relevant. Towards the end

of the cross-case analysis, therefore, the emerging findings were explored in relation to these theoretical ideas, which were incorporated into the findings where it was deemed relevant.

This analysis stopped short, however, of assuming these themes were law-like propositions that could be generalised outside these three cases. The assumption that knowledge is fallible and the feasibility that some relevant factors and contextual conditions were not identified from these three cases prevents the production of law-like prepositions. Rather, the goal was to produce themes that summarise the feasibility of the phenomenon occurring as it did, given the circumstances. This approach is an adapted version of the methods described by Yin (2014), who suggests explanations of phenomena can be treated as either valid or not. The approach taken in this study adapts Yin's methods to be coherent with the assumption stated through this study that reality is unknowable, and knowledge is fallible.

#### 5.7.4.4. Techniques of cross-case analysis

Four main techniques were used to display and explore cross-case data: data matrices, concept mapping, memo writing, and theme writing. The main findings from each case were mapped out into a data matrix (Appendix D) on Microsoft Word, where the rows included summaries of outcomes, factors influencing access to hospice care, and contextual conditions, with each column representing a case. Using the content of this matrix, memos were written summarising cross-case comparisons that had the potential to explain more generally how factors influence access to hospice care. The content of each memo was explored using concept mapping techniques, whereby the content is redrawn on paper into visual concept maps to facilitate the creative process of identifying commonalities and differences between cases and clarifying ideas and terms. Patterns and ideas generated from this process were then summarised in further data matrices, to clarify the differences between cases and attribute relevant quotes. Clarifying the interpretation and meaning of these patterns was also part of the process of writing the cross-case themes. Ongoing interpretation of findings whilst writing results – writing as analysis – is recognised as inherent to any qualitative analysis (Denzin, 2014).

## 5.8. Chapter summary

This study is designed to address a question about the relationship between socioeconomic position and access to hospice care, specifically exploring hospice referrals in socially deprived areas. Built on philosophical foundations drawn from critical realism, the study design recognises the importance of contextual conditions in driving hospice referrals, reflected in the decision to use a case study approach. With a specific focus on the conditions that surround phenomena, a multiple case study approach is well suited for this purpose. In this multiple case study, I draw on statistical and qualitative data to explore the research question, first in each individual case and subsequently in a cross-case analysis. The analytical methods of generalised linear modelling, qualitative thematic analysis, and case study methods feature throughout. The study, therefore, incorporates a mixed methods approach, with qualitative findings used to try to explain quantitative findings. By comparing findings across cases, the intent is to identify repeated patterns in the data relating to hospice referrals and social deprivation, and the conditions that influence them.

# Chapter 6. Results of within-case analysis

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## 6.1. Introduction

As a multiple case study drawing largely on the work of Yin (2014; 2018), the key results of this study are those found through the comparison of cases. These findings (those stemming from the cross-case analysis) are presented in the subsequent chapter and provide the foundation for the discussion towards the end of the thesis. A prerequisite for understanding how the cases compared to one another, however, is to understand the cases individually. This chapter presents the three cases as individual entities, drawing on the relevant quantitative and qualitative results to provide an overview of access to hospice care in the context of social deprivation in each case. The intention is to present background information to the subsequent cross-case findings, which are derived only after the individual analyses of each case.

As outlined in the methods chapter, each case includes an analysis of hospice referral rates, hospice patient characteristics, late referrals, and finally of interviews with referrers and hospice staff. Results from the statistical and qualitative analyses are presented separately, although links are drawn between them where relevant. For ease of reading, some data tables - those relating to univariate Poisson regression analyses, model selection, descriptive statistics, and late referrals - are not included in this chapter but are provided in full in Appendices E-G.

This study considers how areas compare to each other locally and therefore uses regional deprivation ranks rather than national ranks. These are calculated separately for each case, with the range in deprivation ranks differing depending on the geographical size of the hospice catchment area in each case. Figure 6 shows the range of regional deprivation rankings of areas in each case and how the rank numbers correspond to an area being either more or less deprived. In all cases, rank 1 is assigned to the most deprived area and the highest possible rank to the least deprived area. For example, in Case 1 there are 157 areas. The area in Case 1, with the most deprived rank within the national rankings is assigned regional deprivation rank 1 and the area with the least deprived rank within national rankings is assigned regional deprivation rank 157.

The regional deprivation ranks are categorised into regional deprivation quintiles, ranging from quintile 1 (20% most deprived areas) to quintile 5 (20% least deprived areas). Therefore, within each case, each quintile includes approximately the same number of areas.

Most deprived → Least deprived					
Deprivation rank	Rank 1				Case 1: Rank 157 Case 2: Rank 206 Case 3: Rank 92
Deprivation quintile	1	2	3	4	5

**Figure 6: The relationship between regional deprivation rank and quintile**

In interviews, participants were asked primarily about caring for patients in socially deprived areas but they moved between talking about patients in socially deprived areas and talking about patients and families experiencing socioeconomic disadvantage. Consequently, in the interpretation of the qualitative data presented in each separate within-case analysis I also move between these terms, although the primary focus is on caring for patients in socially deprived areas.

## 6.2.Case 1 Results

### **Key findings**

- Referrals in this case were higher in the 20% most deprived areas, but this finding was not statistically significant.
- Hospice patients initially referred to day hospice were more likely to live in more deprived areas than those referred to other services.
- Participants described challenges caring for some patients and families living in the more socially deprived areas of the case, which could require more time and input and may have generated hospice referrals in those areas.

#### **6.2.1. Background to Case 1**

The hospice in Case 1 covers a core population of approximately 200,000 people, residing in 157 Lower Layer Super Output Areas that cover the hospice's core catchment area. The organisation provides a wide range of services for patients and families, including bereavement services, lymphoedema, and complementary therapies. However, this within-case analysis focuses on three hospice services provided in Case 1 relevant to patients in the last year of life: hospice at home, the inpatient hospice, and day hospice. Between September 2016 and September 2018, 2208 patients are referred to one of these services, and the case has an overall hospice referral rate of 10.52 per 1000 population.

Approximately half the population within the hospice catchment area in Case 1 live in a rural area. The majority (76%) are under 65-years-old and 97% are white (see Appendix E Table A.5) for a table of area characteristics in Case 1). Only a small proportion (13%) of areas in Case 1 are among the 20% most deprived areas nationally in England (see Appendix H Table A.19). After being re-ranked into regional deprivation ranks, the most deprived areas in this case tend to be urban and near the coast, have a younger population, and a higher crude mortality (Table 14). Located on the edge of the largest urban area within the catchment area, the hospice is geographically closer, on average, to many of these more deprived neighbourhoods than to the more rural and less deprived areas (Table 14). Table 14 also shows that before adjusting for the effect of other factors, these areas have on average a higher hospice referral rate than

any other deprivation quintile. The second highest referral rate falls in the least deprived quintile, with no gradient in either direction immediately apparent in this exploratory table.

Table 14. Area characteristics by deprivation quintile (Case 1)

Deprivation quintile	Referrals (n)	Referral rate <sup>1</sup>	Mortality rate <sup>1</sup>	Rural (%)	Urban (%)	65+ (%) <sup>1</sup>	Female (%) <sup>2</sup>	Distance (km) <sup>3</sup>	White (%) <sup>2</sup>
Most deprived - 1	540	14.67	13.81	4	37	19	51	5	97
2	395	9.61	9.81	13	27	20	50	12	96
3	393	9.36	10.97	28	11	25	51	16	97
4	382	9.8	11.66	31	9	28	52	16	98
Least deprived - 5	498	11.91	12.86	24	16	29	51	17	98
Total	2208	-	-	100	100	-	-	-	-

<sup>1</sup> Per 1000 population

<sup>2</sup> Mean value for areas in corresponding regional deprivation quintile

<sup>3</sup> Distance to main hospice building

### 6.2.2. Case 1 statistical analysis results

#### *Hospice referral rates*

Hospice referral rates are not statistically significantly associated with area social deprivation in Case 1. While there is a trend towards the most deprived quintile generating more referrals than other areas, this is not statistically significant in the final regression model. The results of exploratory analyses and model comparison for this analysis are provided in Appendix E.

Table 15 reports the incidence rate ratios (IRR) for area characteristics in this analysis; IRRs indicate the proportionate change in referrals with a one unit change in the associated variable. Because they indicate the ratio of change in the rate of referral (rate ratio), the effect is multiplicative. Consequently, a value greater than 1 indicates an increase in hospice referrals (corresponding to a one-unit increase in the independent variable) and a value less than 1 indicates a decrease. The IRR estimate of 1.04 associated with 'most deprived 20%' in Table 15 indicates a higher number of referrals in the most deprived area, with referral rates increasing by a ratio of 1.04 when moving from quintiles 2-5 to quintile 1 (the 20% most deprived areas). Alternatively, this can be understood as a 4% increase in hospice referral rates in the 20% most deprived areas compared to all other areas. However, this is not statistically significant. Table 15 also shows that increases in crude mortality, the proportion of female population in an area, and the proportion of population who are white are associated with an increase in hospice referrals. However, hospice referrals decrease as distance from the hospice increases. All these associations are statistically significant (apart from that calculated for area deprivation).

**Table 15. Change in hospice referral rate by area characteristics (Case 1)**

Variable	IRR <sup>1</sup>
Most deprived 20% <sup>2</sup>	1.04
Crude mortality <sup>3</sup>	1.01*
Distance (km) <sup>3</sup>	0.96*
Female (% of population) <sup>3</sup>	1.05*
White (% of population) <sup>3</sup>	1.06*

\* p < 0.05

<sup>1</sup> The ratio of change in hospice referral rate

<sup>2</sup> Compared to all less deprived areas

<sup>3</sup> IRR corresponds to one unit increase in variable

#### *Analysis of hospice patient characteristics in Case 1*

The second analysis looks at the association between the deprivation of the area where a patient lives and a range of patient characteristics. Using postcode data, each hospice patient is linked to a geographical area, already assigned a deprivation rank. Whereas the previous analysis of hospice referral rates uses deprivation quintile, this analysis of patient characteristics uses deprivation rank. This is because deprivation in this patient characteristics analysis is the dependent ‘outcome’ variable; when used in this way, rank is more intuitive to interpret than deprivation quintile.

Descriptive statistics presented in Table 16 report the mean, median, and interquartile range for the deprivation ranks of areas where patients live, distributed across different characteristics. As described in Figure 6 at the beginning of this chapter, a lower deprivation rank means an area is more deprived; consequently, a higher rank means an area is less deprived. In Case 1, deprivation ranks range from 1 to 157. The first row of Table 16 indicates that patients receiving day hospice lived in areas with a mean deprivation rank of 73.6. For those referred to inpatient care it was 80.1, and for hospice at home 80.3. This suggests that, on average, patients receiving day hospice were from more deprived areas.

Table 16. Hospice patient characteristics by deprivation rank<sup>1</sup> (Case 1)

Hospice patient characteristics		Deprivation rank <sup>1</sup> (assigned to patients)				Univariate analysis	Multivariate analyses	
		Mean	Median	.25	.75		Service analysis	Referrer analysis
Service received	Day hospice	73.6	73	28	121.5	-	-	-
	Inpatient hospice	80.1	81	38	121.5	6.51*	6.96*	-
	Hospice at home	80.3	82	37	126	6.77*	5.97*	-
Referred by	GP surgery	72.7	72	29	112	-	-	-
	Clinical nurse specialist	76	76	30	118.25	3.29	-	3.84
	District nurse	84.3	85	47	128	11.59*	-	11.50*
	Hospice	78.3	80	35.25	121.75	5.56*	-	6.35*
	Hospital	76.8	71.5	33.5	121.75	4.04	-	4.39
	Other	82.5	92	36.75	129	9.79*		9.69*
Diagnosis	Cancer	78.7	79	36	122	-	-	-
	Non-cancer	75.2	73	29	122	-3.51	-	-
Gender	Female	76.6	73	33	122	-	-	-
	Male	78.6	81	35	122	2.01	-	-
Age <sup>3</sup>	-	-	-	-	-	0.26*	0.31*	0.25*

\*p value < 0.05. <sup>1</sup>Possible ranks range from 1 (most deprived) to 157 (least deprived). <sup>2</sup>When comparing patients in different characteristic groups. A higher rank (positive value) corresponds to coming from less deprived areas. Values for services are when compared with patients referred to day hospice; values for referrers are when compared patients referred from GP surgeries. <sup>3</sup>No rank averages provided for age because it is a continuous variable.

The estimated change in deprivation ranks produced by the univariate and multivariate analyses in Table 16 are additive; they indicate the increase or decrease in deprivation rankings corresponding to a change in patient characteristic. The change in deprivation rank for inpatient and hospice at home services are both positive (6.96 and 5.97 respectively in the multivariate analysis,  $p < 0.05$ ). This indicates an increase in rank; patients referred to those services tended to come from less deprived areas than those referred to the day hospice service. While potentially suggesting a socioeconomic pattern to referrals, this result should be treated with caution. Data on service is missing for 21% of patients in case 1 (see Appendix I Table A.21). Of these, 27% are patients living in the most deprived quintile of Case 1 (Appendix I Table A.21). Hospice staff in Case 1 are unsure why data would be missing about services received; a lengthier discussion of this limitation can be found in Chapter 8.

Patients referred by district nursing teams in Case 1 appear to come from less deprived areas than those referred by GP surgeries (11.50,  $p < 0.05$ ). Age is also associated with a small but statistically significant increase in deprivation rank in both multivariate analyses (0.31 and 0.26,  $p < 0.05$ ), indicating that increasing patient age is associated with living in a less deprived area (Table 16). While there are small differences in the average deprivation rank of patients with cancer and those with non-cancer conditions, this is not statistically significant. This is also the case for gender. The analysis of late referrals is not presented here (see Appendix G) but suggests there is no statistically significant association between the deprivation rank of the area where a patient lives and how close to death they are when referred.

Overall, the statistical analysis of referrals in Case 1 finds that while referral rates are highest in the most deprived quintile, this difference is not statistically significant once other factors are taken into account. Additionally, the analysis of patient characteristics found that hospice patients initially referred to day hospice are more likely to live in more deprived areas than those referred to other services. This suggests a pattern in referrals across different areas of deprivation that warrants further exploration.

#### **6.2.3. Summary of findings from interview data in case 1**

Experiences of generating and responding to hospice referrals are explored in interviews with eleven participants involved in providing end-of-life care in Case 1, considering how different factors may be influencing access to hospice, and more broadly end-of-life care, in more socially deprived areas. Seven

of these participants are referrers, including five GPs and two nurses, and the remaining four participants work for the hospice (Table 17).

**Table 17. Interview participants (Case 1)**

Pseudonym	Participant group	Role
Adi	Referrer	Specialist Nurse
Elizabeth	Referrer	District Nurse
Jonathan	Referrer	GP
Tom	Referrer	GP
Jessica	Referrer	GP
Ben	Referrer	GP
Hugh	Referrer	GP
Hannah	Hospice	Senior Hospice Staff
Claire	Hospice	Senior Hospice Nurse
Alice	Hospice	Senior Hospice Nurse
Trudy	Hospice	Senior Hospice Nurse

### *Introducing themes from Case 1*

Participants speak of challenges in their interactions with patients and families in the context of social deprivation that lead to healthcare professionals providing greater input into care. This could feasibly trigger referrals in the more deprived areas as professionals seek support from other care providers. These challenging consultations are described in three distinct but related themes for this case, as detailed in the sections below. Briefly, the first theme reflects participants' apparent desire for patients and families of patients to be proactive in taking responsibility for care, and the difficulty they see some families in socially deprived areas have with this. This was characterised as 'difficulties taking ownership' (theme 1), which reflects participants' perception of the difficulties patients and families have being proactive and independent in tasks involved with care management. Part of this difficulty is associated by healthcare professionals with the high level of psychological needs among some patients and families in socially deprived areas. In light of this, participants reflect on their own and others' skillset around psychological care, as characterised in the theme 'skills for psychosocial care' (theme 2). Finally, interactions are intractable from the resources and organisational context in which participants work. Healthcare professionals in this study reflect this when speaking about 'appropriate use of time' (theme 3), with perception of resources differing between areas. Collectively, these themes suggest that consultations and visits with patients in the last year of life may be more time intensive, requiring multiple and longer visits, with professionals seeking support from other services.

#### 4.2.4 Detailed themes for Case 1

The data from the interviews can be summarised in three themes: difficulties taking ownership; skills for psychosocial care; and appropriate use of time.

##### **Theme 1: Difficulties taking ownership**

Several participants feel that some patients and families have difficulties taking ownership of the situation as a patient's illness worsens and their needs increase, creating challenges for professional care. Jonathan, a GP working in a deprived neighbourhood, describes differences he observes between patients and families in different socioeconomic groups:

...you tend to find those [from affluent backgrounds] have a partner who steps up and becomes the main carer... very organised in what needs to be done and what to expect, and has often done a lot of reading around the condition, erm, so understands what is needed, what support is there... The lower socioeconomic groups, you tend to have this almost, this sense of, well there is nothing we can do as a family, it's the medical services that have to provide that support, there is something wrong, you need to come and sort it out. (Jonathan, Referrer GP, Case 1)

Jonathan and others describe experiencing difficulties reaching a common understanding with families in more disadvantaged socioeconomic circumstances about their roles in managing the care of patients. Participants feel frustrated but, on the most part, sympathetic with patient and family circumstances, recognising the difficulty of proactively prioritising health when faced with other challenging social or financial issues. Reactions to this challenge varied. One GP who feels they do not have sufficient time with patients says it is “too much to train or tease apart” (Jonathan, Referrer GP, Case 1) to help families understand they may have a role. In contrast, a nurse who can spend considerably more time with a patient uses motivational interviewing techniques to encourage self-efficacy and resilience among patients and families:

...that's about not thinking that's your problem...get them to be a bit more independent, a bit more resilient, but it's easier said than done. (Adi, Referrer Specialist Nurse, Case 1)

Whether the issues referrers identify are to do with understanding, competing priorities, family self-efficacy with caring, or something else entirely, each can be described broadly as an example of ‘difficulty taking ownership’. Exactly how that difficulty influences access to hospice care depends on further factors, including the complex needs of patients and the time and resources available to professionals caring for patients in the last year of life.

### **Theme 2: Skills for psycho-social care**

Participants describe high levels of psychological need amongst patients and families in the more deprived areas of Case 1, due in a large part to prevalence of pre-existing mental health problems. Adi summarised this as:

...before the palliative diagnosis they've got extreme complex psychological issues that have never been addressed, never been resolved, and then you've got that death diagnosis on top of that and that actually exacerbates everything that's happened in the past... We need to try and unpick what the problems are to actually help best support them. A lot of the time you're just fire-fighting and dampening that fire down and it blows back up again...I try to do what I can for the patients, you do. But if you don't put a lid on that problem, you actually will have a death that is very, very unpleasant and there have been a couple that you, you, it's there at the back of your head all of the time. (Adi, Referrer Specialist Nurse, Case 1)

Although several recognise that psychological distress can occur for patients and families in any socioeconomic group, some participants are clear that this sort of burden, at least the way it is expressed, is noticeably different among families experiencing socioeconomic disadvantage to those in more advantaged socioeconomic circumstances. Referrers speak of consultations where the patient's needs would get "mixed in together" (Jonathan, Referrer GP, Case 1) with family anxiety, or having to use "all your communication skills" (Claire, Hospice Senior Nurse, Case 1).

While the need for psychosocial care for patients in deprived areas appears strong, the ability to recognise and to care for these needs varies between providers, and between professionals within those providers. Referrers judge the hospice staff's ability to provide psychosocial care in relation to their own skills in that area, and the skills and resilience of other teams. Even if the hospice is not viewed as highly skilled, hospice services were used to provide practical support and to relieve the pressure caused by patient and family psychological distress in more deprived areas. Several participants link the high burden of mental health issues towards the end of life to the absence of accessible high-level psychological care for severe mental illness in the more deprived areas.

Participants also speak about times about when the hospice services seem to match well with what some patients needed. For example, several referrers see the day hospice as an appropriate service for patients struggling with symptoms related to respiratory conditions. While relevant across different socioeconomic areas, this is particularly raised as an issue faced by patients in difficult socioeconomic circumstances, and may explain the higher number of referrals to day hospice in these areas in this case. However, the difficulty referring patients and families who do not want to attend day hospice or who are

unable to due to being housebound – both of which are linked by participants to socioeconomic disadvantage – also suggests there is a cohort of patients not benefitting from this who could.

### **Theme 3: Appropriate use of time**

In this case, participants describe consultations with some patients and families living in socially deprived areas as more time intensive, requiring multiple and longer visits. This is partly related to the challenges outlined above – patients' psychosocial needs and difficulties taking ownership over their care – but also to issues with primary care resources in the socially deprived areas in this case. One participant who had worked in other socially deprived neighbourhoods outside the case describes the area as having particular poor continuity and primary care access. Speaking about the consequence of this, Hugh says:

...if you're just charging round like a headless chicken kind of thing you, you ended up dealing with the crisis problem and actually a lot of the problem with all this kind of care is it's actually having the time to provide it...it's very easy just to go into someone's house when they've got a chest infection or something and see them and give them antibiotics or something but if they've actually got end stage COPD and they've got a huge list of medicines that they've built up over the years, you know the time to, to look at their needs, move from a kind of disease focus thing to a more holistic thing, de-prescribe, talk about what support they've got, talk about advanced care and all those kind of things, you know, it's time consuming to do it properly. (Hugh, Referrer GP, Case 1)

Much of the discussion around time is about appropriate use of time given limited resources and alternative services. GPs across different areas of deprivation talk about wanting to do more for palliative care patients, as well as enjoying the experience of providing good palliative care. Those in generally more affluent areas emphasise resource challenges relating to hospice bed availability:

I think the main way it can be overstretched is not have the hospice beds when you want them...  
(Ben, Referrer GP, Case 3)

In contrast, those working in predominantly more deprived areas recognise this but tend to emphasise primary care resource issues leading to a lack of continuity and not having enough time to spend with patients:

Massively overstretched. I don't think I do have the time to manage them, erm, as well as I'd like to. (Hugh, Referrer GP, Case 1)

Referrers having more time to spend with patients in the less deprived, rural areas is also cited as a reason by some hospice staff for lower than expected referrals from those areas. Not having enough time to spend with patients in primary care in more deprived areas appears to influence access to hospice care in several ways. One referrer explains that the sheer number of visits to patients who saw the GP as the first point of call led to them bringing in other services, including the hospice, to deflect patients' concerns upon. Another describes patients associating poor access to a GP earlier on in their life with late diagnosis of a serious illness, leading to high levels of mistrust between patients, families and primary care that took time to overcome. This led to that professional managing expectations and only offering hospice services if they can be sure the patient will actually receive them, to prevent any further breakdown in trust.

#### **6.2.4. Summary of Case 1**

While there were comparatively high referral rates in the most socially deprived areas in this case this trend did not reach statistical significance in the multivariate analysis. It is difficult to explain non-significant findings, indicative of low levels of certainty about the effect of social deprivation, using the qualitative data. However, the findings from the qualitative analysis in Case 1 point towards several factors that may lead to participants turning to the hospice for input into the care of patients and families living in socially deprived areas. This includes, for example, time and resource pressures, and the psychosocial needs of patients and families. While this analysis cannot capture the precise effect of these factors, evidence in this case suggests that organisational context in the wider healthcare system – and its relation to deprivation – is a driver of hospice referrals at the end of life in Case 1.

## 6.3. Case 2 Results

### 6.3.1. Background to Case 2

#### Key findings

- There was no evidence that referral rates differed (statistically significantly) between different areas of deprivation.
- Hospice patients initially referred by hospitals were more likely to live in more deprived areas than those referred by GP surgeries.
- Participants described access issues with GP surgeries and high levels of integration with hospital settings that could explain the referral patterns observed in this case.
- Participants also described the challenges navigating between a desire to “rescue” patients and accepting the difficult circumstances of some people’s lives.

The catchment area covered by the hospice in Case 2 serves a population of just below 190,000, living in 206 Lower Layer Super Output Areas. Case 2 focuses on referrals to six hospice services for patients: a hospital-based service, community services, hospice at home, inpatient, outpatient consultations, and day hospice. Referral data indicates that 5626 individual patients are referred to one of these hospice services between April 2016 and April 2019. The hospice referral rate for that period in Case 2 is 22.86 per 1000 population.

Most (91%) of the catchment area of Case 2 is urban and an estimated 97% of residents are white and 76% are under 65-years-old (see Appendix E Table A.5 for a table of area characteristics in Case 2). Most the areas in the catchment area of Case 2 are more deprived than the English average, with 30% falling in the 20% most deprived areas nationally (see Appendix H Table A.19). After being re-ranked into regional deprivation ranks, the most deprived areas are largely concentrated in either a large coastal town or a more isolated and smaller coastal town. All of the 40% most deprived areas in this case are urban (Table 18). Areas in the most deprived quintile of Case 2 have on average a younger population, with a slightly smaller proportion of female and white residents (Table 18). They produce the fewest number of referrals, corresponding to the second lowest referral rate (after the least deprived 20%) once population sizes are considered.

Table 18. Area characteristics by deprivation quintile (Case 2)

Deprivation quintile	Referral (n)	Referral rate <sup>1</sup>	Mortality rate <sup>1</sup>	Rural (%)	Urban (%)	65+ (%) <sup>1</sup>	Female (%) <sup>2</sup>	Distance (km) <sup>3</sup>	White (%) <sup>2</sup>
Most deprived - 1	975	21.16	12.35	0	22	15	49	5	96
2	1076	23.06	14.83	0	22	22	51	4	97
3	1357	27.14	15.63	11	21	26	52	6	98
4	1224	23.91	14.63	42	18	28	52	7	98
Least deprived - 5	994	19.13	11.31	47	17	28	51	8	98
Total	5626	-	-	100	100	-	-	-	-

<sup>1</sup> Per 1000 population  
<sup>2</sup> Mean value for those areas  
<sup>3</sup> Distance to main hospice building

### 6.3.2. Case 2 statistical analyses

#### *Hospice referral rates*

Hospice referral rates are not statistically significantly associated with area deprivation in Case 2. This analysis demonstrates the importance of including deprivation in a multivariate analysis when trying to assess any inequities in referrals. While the raw number of referrals from the most deprived areas are lower than from other areas, when differences in population size, mortality, age structure, and other factors are taken into account, the 20% most deprived areas are associated with an increase in hospice referrals (Table 19). However, as the results in Table 19 indicate, this does not reach statistical significance in the final model (see Appendix E for comparison of model fit).

Table 19 reports the incidence rate ratios (IRR) for variables included in the final hospice referrals model for Case 2. As in Case 1, these IRRs indicate a change in hospice referrals with a one-unit change in the associated variable, with a value greater than 1 indicating an increase in hospice referrals with a one-unit increase of the corresponding variable and less than 1 indicating a decrease. In this case, hospice referral rates increased by 9% (a rate ratio of 1.09) in the 20% most deprived areas, compared to all other areas, although this is not statistically significant (Table 19).

**Table 19. Change in hospice referral rate by area characteristics (Case 2)**

Variable	IRR <sup>1</sup>
Most deprived 20% <sup>2</sup>	1.09
Crude mortality <sup>3</sup>	1.04*
Over 65 (% of population) <sup>3</sup>	1.01*
Urban area	1.22*
Distance (km) <sup>3</sup>	0.99
Female (% of population) <sup>3</sup>	1.00

\* p < 0.05

<sup>1</sup> The ratio of change in hospice referral rate

<sup>2</sup> Compared to all less deprived areas

<sup>3</sup> IRR corresponds to one unit increase in variable

#### *Analysis of hospice patient characteristics in Case 2*

Switching from deprivation quintiles used in the first analysis to deprivation rank, Table 20 presents results from the analysis of patient characteristics and area deprivation in Case 2. In this analysis, each hospice patient is linked to an area assigned a regional deprivation rank, with ranks ranging from 1 to 206. Results presented in Table 20 indicate that patients initially referred from hospitals in Case 2 tend to come from more deprived areas than those referred by GP surgeries. A change from being referred from hospice to being referred from GP surgery corresponds to 5.97 increase in rank (p < 0.05), suggesting patients referred from GP surgeries are from less deprived areas. There are no observed differences in the initial service patients in deprived areas are referred to. Patients who are younger are more likely to be from more deprived areas (increasing age associated with an increase in rank in Table 20).

Table 20. Hospice patient characteristics by deprivation rank<sup>1</sup> (Case 2)

Hospice patient characteristics		Deprivation rank <sup>1</sup> (assigned to patients)				Univariate analysis	Multivariate analyses	
		Mean	Median	.25	.75		<i>Service analysis</i>	<i>Referrer analysis</i>
Change in deprivation rank <sup>2</sup>								
Service received	Hospital	103.8	103	56	152		-	-
	Community	104.6	103	56	152	0.81	2.82	-
	Day	101.3	100	56	144.25	-2.49	-0.69	-
	Hospice at Home	107.7	107	64	151	3.84	-0.85	-
	Inpatient	88.9	91	35.5	132	-14.92	-10.18	-
	Outpatient consultation	102.1	93	69.5	136.5	-1.68	3.34	-
Referred by	Hospital	103.2	102	56	151	-	-	-
	GP surgery	108.7	111	62	153	5.61*	-	5.97*
	Community	93.7	83.5	52.8	142.8	-0.49	-	-10.05
	Internal	96.4	99	44	140.5	-6.75	-	-4.37
	Out of hours	107.7	107	64	151	4.51*	-	-0.89
	Other	144.8	151	118	175.8	41.66*	-	42.03*
Diagnosis	Cancer	105.2	106	56	152		-	-
	Non-cancer	103.4	102	58	149	-1.71	-	-
Gender	Female	105.7	105	60	152		-	-
	Male	103.3	102	56	151	-2.43	-	-
Age <sup>3</sup>	-	-	-	-	-	0.53*	0.55*	0.55*

\*p value < 0.05. <sup>1</sup> Ranks range from 1 (most deprived) to 206 (least deprived). <sup>2</sup> When comparing patients in different characteristic groups. A higher rank (positive value) corresponds to coming from less deprived areas. Values for services are when compared with patients referred to hospital-based hospice care; values for referrers are when compared patients referred from hospital. <sup>3</sup> No rank averages provided for age because it is a continuous variable.

In summary, there is no strong evidence that overall hospice referral rates are associated with area deprivation in Case 2. Additional analyses of patient characteristics suggest that hospice patients initially referred by hospitals are more likely to live in more deprived areas than those referred by GP surgeries. This statistical finding is further explored in light of the qualitative interview data in the section below.

### 6.3.3. Summary of findings from interview data in Case 2

The experiences of fourteen healthcare professionals (eight referrers, five hospice staff) in relation to these findings and others are explored in interviews.

**Table 21. Interview participants (Case 2)**

Pseudonym	Participant group	Role
Rachael	Referrer	District Nurse
Francis	Referrer	Senior Community Nurse
Harriet	Referrer	Specialist Nurse
Carrie	Referrer	Specialist Nurse
Louise	Referrer	Specialist Nurse
Lisa	Referrer	Specialist Nurse
Jane	Referrer	GP
Clara	Referrer	GP
Kate	Hospice	Senior Hospice Clinician
Becky	Hospice	Senior Hospice Clinician
Caitlin	Hospice	Senior Hospice Clinician
Val	Hospice	Senior Hospice Nurse
Carol	Hospice	Senior Hospice Nurse
Paula	Hospice	Senior Hospice Nurse

#### *Introducing the themes in Case 2*

Participants in this case speak about how the organisation of services can be a barrier and facilitator to hospice referrals. They describe a broken system within primary care where patients and families struggle to obtain or attend appointments, partly because of resource issues, but also demands on some patients in socially deprived areas mean they struggle to fit the requirements of the system. This is reflected in the first theme ‘not fitting into a broken system’. However, in Case 2, the hospice’s ‘integration with hospital care’ (theme 2) was integral to hospice referrals in the area. This had a potentially disproportionate (and advantageous) effect on populations in socially deprived areas who may be more

likely to access hospital care and thus receive a referral via that setting. The subsequent two themes attend more to the nature of interactions between professionals and patients both before and after a hospice referral. Participants speak about their perception of ongoing 'resistance to care, rather than to referral' (theme 3) among some patients and families in socially deprived areas. This, and other observations about living in the context of social deprivation, led to participants reflecting on how professionals wrestle with 'accepting not rescuing' (theme 4) patients. Collectively, these themes demonstrate the influence different factors can have on access to hospice care, both before and after a referral.

#### **6.3.4. Detailed findings from interviews in Case 2**

##### **Theme 1: Not fitting into a broken system**

A number of factors help to create an environment in primary care, particularly in GP surgeries, in socially deprived areas in Case 2 that may not be conducive to making an initial referral to hospice care. Many participants speak about patients struggling to obtain or attend appointments with GPs. Some find it difficult to give reasons for this, although others suggest that patients may downplay symptoms, have other priorities, or not pick up issues before a crisis occurs:

I don't mean to generalise, but often the patients [in socially deprived areas] don't shout very loud. They often don't ask. They often don't, you get patients 'sorry to bother you, didn't want to, I've had it for five months but didn't want to bother you' or 'there was no appointments so I didn't think it was urgent, there's people that need it more than I do'... (Jane, Referrer GP, Case 2)

However, patients in socially deprived areas are also negotiating access in what one participant described as a broken system, where resources are considered overstretched due to shortages of GPs and perceived high demand for same-day appointments. Participants describe issues patients have making appointments with GPs, although this is thought to vary between practices. A system unable to provide consistent ease of access to primary care coupled with patients less likely to emphasise their needs feasibly creates an environment in which it is difficult to identify a need for hospice care and then make the initial referral.

## **Theme 2: Integration into hospital care**

It is plausible that patients in socially deprived areas who might not access primary care or engage in planned end-of-life care will be more likely to reach out to healthcare services when care needs become urgent. Several participants suggest that this might be the case. Here Kate describes the circumstances in which some patients may be introduced to hospice care via a hospital admission:

I think there is also that element of patients not asking for it, not expecting it, and, and then people not thinking of it either until they end up in hospital, where there is a much, I suppose stronger thought oh what's going to help keep this patient out of hospital, what can we do to make this as good as it can be which then trigger that. (Kate, Hospice Senior Clinician, Case 2)

Observations made by Kate and others are supported by the finding that patients initially referred to hospice care from the hospital are more likely to be from deprived areas than those referred by GP surgeries. Facilitating that transition from acute care to hospice care in this case is the hospice's approach to integrating their services, with a hospice service closely integrated into the large local hospital. Hospice staff believe the physical location at the hospital is particularly important as it facilitates access to patients and staff, with an environment arguably better suited to ongoing interaction and education with referrers than in the community:

Yeah, we do have really good working relationships with the teams within the hospital. They are good at referring, they are good at ringing for advice when they need it. You quickly build up those relationships when you are on the wards day to day. (Paula, Hospice Senior Nurse, Case 2)

...how the hospital team works is that, erm, they will pick the referrals up really triage them very quickly but find that it's easier to just go and have a look and see you know, these patients. They can get to them very quickly. So, whereas the community team might have a two hour round trip for one patient, they literally walk across the car park to get to the main building to go and see a patient. (Val, Hospice Senior Nurse, Case 2)

Integrating the care this way helps facilitate the transition of a larger number of patients, particularly those who are more likely to be admitted to hospital near the end of life, such as patients from more deprived areas.

### **Theme 3: Resistance to care, not to referral**

The general emphasis in the Case 2 interviews is not on the absence of referrals but rather the challenges around patients engaging with hospice and other services in a way that fits hospice notions of appropriate end-of-life care. Participants describe how the social environment in which patients and families live could affect their ability to get the most out of a hospice service. Examples were varied, reflecting the diversity of people's lives in socially deprived areas, but often describe people holding services at arm's length. These include patients guarding against a perceived risk of illicit drugs or alcohol being taken away, not wanting uniformed staff in the home, or not accepting the support of end-of-life care services due to negative encounters with previous services in their lives. Val shares one such example:

But, erm, for quite a while she was very, very standoffish. She really didn't want to know. A lot of that was at 23 who wants to talk about dying? But it was about "well you know how you gonna help me? Nobody helped me in the past." Quite flippant. (Val, Hospice Senior Nurse, Case 2)

Although participants often mention chaotic lives as a reason why some patients and families do not engage in services, this term risks presenting the behaviours of patients as unpredictable or irrational. As the above examples demonstrate, these behaviours may be expected and reasonable given a patient's past or current experiences. Other examples of disadvantaged patients having lower expectations of services are described in passive rather than defensive terms, with patients appearing grateful and surprised when "simple things happen" (Kate, Hospice Senior Clinician, Case 2). For some participants, this observation stands out because it contrasts with a perception that more socioeconomically advantaged patients have higher expectations of hospice care:

I think in terms of the community service, whose expectations are greater of palliative care, that would be your more affluent areas. Whose more grateful for what they receive that would be your less affluent areas. (Carol, Hospice Senior Nurse, Case 2)

As to how the above behaviours influence referrals, there is little evidence that the suggestion of a hospice referral was met with more resistance from socioeconomically disadvantaged populations than others. However, it is feasible that conversations about end of life might become more difficult if referrers themselves also encounter some of the above challenges in consultations. However, the contribution of evidence from referrers in the community is small in this case, making it difficult to interrogate this. As described above, the general emphasis in the available data is of barriers to engaging with end-of-life care after referral rather than the absence of referrals.

#### **Theme 4: Accepting not rescuing**

Several participants describe a professional conflict between wanting to help a patient and accepting the circumstances that some disadvantaged patients live in, as Rachel describes:

I mean obviously you go into a classroom and you are taught end-of-life care and out in community it's extremely different ... you go out there in community and we had a gentleman quite recently who just lived in absolute squalor, erm, and they are, they are the bosses in their own house really ... if they've got the capacity, then you know you have to respect that as much as you would like to scoop them up, put them in a lovely warm hot bubbly bath and comb their hair and cut their nails and everything, you know, you can't always give what you would love to give, you do have to respect the patient. (Rachel, Referrer District Nurse, Case 2)

Although Rachel is a district nurse, evidence related to this theme primarily comes from hospice staff. The statement from one participant that hospice staff “like to rescue everybody” (Val, Hospice Senior Nurse) suggests the dilemma may be particularly present among this professional group. Although this did not directly help to explain referrals into hospice care, the strength with which some participants speak about this dilemma suggests it is an important experience for those providing end-of-life care for patients in socially deprived areas. Examples are usually about the condition of the home environment,

as the extract from Rachel's interview above demonstrates. Others speak about nurses struggling with being unwanted, allowing patients to make decisions that they disagreed with, or accepting the general chaos in someone's life. Faced with this predicament on a semi-regular basis, several participants have reflected on this tension prior to taking part in this research, coming up with a resolution that allowed them to cope emotionally with providing care in less than "ideal circumstances". Here, Becky describes discussions she had with other team members about responding to these circumstances:

I can remember having a number of conversations saying if this is what this person has chosen, if this is their life and this is their choice about their life, then we should not at the end of their life be insisting that they have to have it all neat and tidy and a proper bed and a proper this and a proper that. (Becky, Senior Hospice Clinician, Case 3)

Similar to Becky's emphasis on the value of patient choice, others accept patients have the right to personalised care or to make their own decisions, even when this is challenging for services and healthcare professionals. Some also reflect on palliative care coming in at the end of someone's life when a way of living that is difficult for clinicians to understand feels normal to the patient. However, there is also an example of services trying to persuade a patient out of a complicated living circumstance when he wants to stay at home. Given that several participants speak about staff finding it difficult to accept patients dying in less than ideal circumstances, and have themselves also wrestled with this, it is possible that for many the first reaction to caring for someone in a socially deprived situation is the desire to 'rescue' or remove them from the situation.

#### **6.3.5. Summary of Case 2**

The hospice's integration with the hospital coupled with seemingly poor access to GP care may explain some of the observed referral patterns in Case 2. Participants in this case tend to emphasise experiences of providing ongoing care to patients in socioeconomically disadvantaged circumstances, rather than any perceived issues with referrals. This revealed tensions between the idea and reality of end-of-life care in socially deprived areas which, while not directly related to referrals, provides some context to the sometimes challenging environment in which hospice care is provided in socially deprived areas in this case.

## 6.4. Case 3 Results

### **Key findings**

- Hospice referrals were lower in the 20% most deprived areas of this case but this was not statistically significant.
- Hospice patients referred from hospitals tended to be from more socially deprived areas than those referred from other providers.
- Healthcare professionals described strong family networks and a culture of resisting input from healthcare services in socially deprived areas of this case, potentially until a crisis occurs, that may have explained hospice referral patterns in this case.

#### **6.4.1. Background to Case 3**

The third case concerns the referral of patients to a hospice at home nursing service between April 2016 and December 2019. The hospice organisation in this case does not have inpatient or day patient services but provides a home-based nursing service, bereavement care, a lymphoedema service, and some other one-to-one support services delivered by staff and volunteers. Focusing on services aimed at patients at the end of life, this case study looks only at the home nursing services. This home nursing service covers a population area of around 140,000, living in 92 Lower Layer Super Output Areas. During the time period of the case, 865 individual patients are referred to the home nursing service, which equates to an overall hospice referral rate of 7.79 per 1000 population.

Geographically, the area in Case 3 is characterised by close-knit communities isolated from cities and scattered about in small towns and predominantly rural areas. Approximately 99% of this population is white, 78% aged under 65 and most (61%) live in a rural area (see Appendix E Table A.5 for a table of area characteristics). Most areas in Case 3 are more deprived than the English average, with 25% of the catchment area falling within the 20% most deprived areas nationally and only 11% in the 20% least deprived areas nationally (see Appendix H Table A.19).

Case 3 has a higher proportion of rural areas within the most deprived 20% of the catchment area than in other cases (Table 22). While acknowledging this, deprivation is still associated with urban areas in

this case. Areas in the most deprived quintile have on average a slightly younger population and the highest crude mortality rates, but there is no immediately clear pattern to hospice referrals across deprivation quintiles (Table 22).

Table 22. Area characteristics by deprivation quintile (Case 3)

Deprivation quintile	Referral (n)	Referral rate <sup>1</sup>	Mortality rate <sup>1</sup>	Rural (%)	Urban (%)	65+ (%) <sup>1</sup>	Female (%) <sup>2</sup>	Distance (km) <sup>3</sup>	White (%) <sup>2</sup>
Most deprived - 1	176	7.41	13.84	18	25	20	50	10	99
2	171	8.35	10.89	14	28	19	51	15	99
3	128	6.62	11.58	20	19	24	49	17	99
4	179	7.41	9.5	30	3	24	51	15	99
Least deprived - 5	211	8.36	9.65	18	25	25	50	11	99
Total	865	-	-	100	100	-	-	-	-

<sup>1</sup> Per 1000 population

<sup>2</sup> Mean value for those areas

<sup>3</sup> Distance to main hospice building

#### 6.4.2. Case 3 statistical analysis results

##### *Hospice referral rates*

As in the other cases, referrals to hospice care in Case 3 are not statistically significantly associated with area deprivation in the final regression model. However, the difference between this result in Case 3 and those in the other cases is in the direction of the effect. In the multivariate analysis for Case 3, the more deprived areas are associated with a decrease in referral rate, when compared to all other areas, as indicated by the Incidence Rate Ratio (IRR) for the ‘most deprived’ variable in Table 23. In this case, referrals fall by an estimated 12% (an IRR of 0.88) as deprivation worsens (comparing the most deprived 20% with all other areas). However, this does not reach statistical significance in the final model, the results of which are presented in Table 23 (see Appendix E for details about model selection).

**Table 23. Change in hospice referral rate by area characteristics (Case 3)**

Variable	IRR <sup>1</sup>
Most deprived 20% <sup>2</sup>	0.88
Crude mortality <sup>3</sup>	1.04*
Distance (km) <sup>3</sup>	0.99*

\*p < 0.05

<sup>1</sup> The ratio of change in hospice referral rate

<sup>2</sup> Compared to all less deprived areas

<sup>3</sup> IRR corresponds to one unit increase in variable

### *Analysis of patient characteristics in Case 3*

This section reports results from the analysis of patient characteristics in Case 3. Each hospice patient is linked to an area, already assigned a deprivation rank, with ranks in Case 3 ranging from 1 (most deprived) to 92 (least deprived). Again, this part of the within-case analysis uses deprivation rank rather than quintile. Descriptive statistics presented in Table 24 report the mean, median, and interquartile range for the deprivation ranks assigned to patients, distributed across different characteristics.

Patients referred from the hospital have a lower mean rank than those referred from other groups, suggesting they come from more deprived areas. This difference is statistically significant when compared to community-based referrers (clinical nurse specialists and district nurses) in univariate and multivariate analyses (Table 24). In the hospice records, the source of referral is recorded for many patients just as 'other healthcare professionals' ('other HCP' in Table 24); hospice staff suggest this would include referrals from specialist areas such as respiratory or heart failure services.

Table 24. Hospice patient characteristics by deprivation rank<sup>1</sup> (Case 3)

Hospice patient characteristics		Deprivation rank <sup>1</sup> (assigned to patients)					Univariate analysis	Multivariate analysis (referrer only)
		Mean	Median	.25	.75	Change in deprivation rank <sup>2</sup>		
Referred by	Hospital	43	42	18	68	-	-	
	Clinical nurse specialists	50.8	54	25	74.75	7.8*	7.63*	
	District nurses	51.1	55	32	70	8.05*	7.04*	
	Informal	53.1	57	37	74	10.09*	9.11*	
	Hospice	63.3	58	51	73	20.32	20.07	
	Other (non-HCP) <sup>3</sup>	51.6	35	35	86.5	8.59*	7.57*	
	Other (HCP) <sup>3</sup>	47.5	50	21	73.5	4.48	3.83	
Diagnosis	Cancer	49.6	53	25	74		-	
	Non-cancer	47.4	47	26	69	-2.17	-	
Gender	Female	48.9	50	26	74		-	
	Male	48.9	52.5	23.5	72.5	-0.03	-	
Age <sup>4</sup>	-	-	-	-	-	0.14*	0.11	

\*p value < 0.05. <sup>1</sup> Ranks ranged from 1 (most deprived) to 92 (least deprived). <sup>2</sup>When comparing patients in different characteristic groups. A higher rank (positive value) corresponds to coming from less deprived areas. Values for referrer are when compared with patients referred from hospital. <sup>3</sup>HCP= Healthcare professional. <sup>4</sup> No rank averages provided for age because it is a continuous variable.

Patient age is also associated with area deprivation, with younger patients tending to be from more deprived areas. However, the magnitude of this association is small and not statistically significant in the multivariate analysis, with a one year increase in age corresponding to a 0.11 increase in rank (becoming less deprived) (Table 24). There is no association between diagnosis of hospice patients and deprivation, nor between gender and deprivation. As with the other two cases, deprivation is not associated with late referral to hospice care (see Appendix G for details of late referrals analysis).

#### **6.4.3. Summary of findings from interview data in Case 3**

Case 3 includes data from seventeen participants, provided in fifteen interviews (two were group interviews, with two participants in each group) in this case. The vast majority of participants are healthcare professionals who can refer patients to the hospice home nursing service; two are employees of the hospice organisation (Table 25).

##### *Introducing the themes in Case 3*

Participants make a number of observations about the lives of patients and families that could feasibly lead to fewer referrals from more deprived areas. Many raise the existence of strong family networks in these areas, with some suggesting this may lead to less reliance on healthcare services. This is described in the theme ‘family resources in deprived areas’ (theme 1). However, healthcare professionals also describe patient behaviours that, collectively, may indicate a culture of resistance to input from healthcare services until a crisis occurs, feasibly leading to patients seeking urgent care rather than primary care, as described in the theme ‘causes and consequences of getting on with it’ (theme 2). Finally, these circumstances may interact with the model of hospice care in such a way as to deter referrals. There is some evidence of the difficulties ‘fitting untypical dying into a narrow hospice model’ (theme 3) and the consequences this may have for patients and families in socially deprived areas.

**Table 25. Interview participants (Case 3)**

Pseudonym	Participant group	Role
Tessa	Referrer	District Nurse
Linda	Referrer	District Nurse
Nadine	Referrer	District Nurse

Frankie	Referrer	District Nurse
Polly	Referrer	District Nurse
Moira	Referrer	GP
Susan	Referrer	GP
Simone	Referrer	GP
Theresa	Referrer	GP
Chris	Referrer	Urgent Care GP
Ian	Referrer	Urgent Care GP
Phillipa	Referrer	Specialist Nurse
Sheila	Referrer	Specialist Nurse
Arlene	Referrer	Specialist Nurse
Francesca	Referrer	Hospital Clinician
Nicola	Hospice	Senior Hospice Nurse
Connie	Hospice	Senior Hospice Nurse

#### **6.4.4. Detailed findings from interview data in Case 3**

##### **Theme 1: Family resources in socially deprived areas**

The prevalence of close-knit family networks is raised as a characteristic of the areas served by the hospice in this case, with both referrers and hospice staff associating this with more socially deprived areas:

Yeah, I can think on the positive side to these people they often have very good family support because these areas are often quite sort of you know they have the traditional family model still. So, in the middle of W1 or W2 for example, which as I suppose you know has quite pockets of social deprivation, they still seem to be able to maintain a good family network. (Ian, Referrer Urgent Care GP, Case 3)

I think the problems are different...but what I find is that people who are in more deprived areas they have better family support. Not always but they do seem to have that support. (Connie, Hospice Senior Nurse, Case 3)

This could have consequences for hospice referrals given that participants commonly cite night support and respite for family carers as key reasons for referring patients to the hospice nursing service. It was

suggested by one hospice staff member that carers who are unemployed may have more capacity to provide long term care and therefore struggle less and require less input, whereas carers in employment become exhausted quicker and need input from the hospice. In contrast, two GPs struggle to identify a trend between social deprivation and how much family support someone has towards the end of life:

So, it's more I would say the differences you see depend on the individual person and their thoughts and beliefs and the family support they've got around or the friends support they've got around them. Which doesn't necessarily tally with social deprivation. (Susan, Referrer GP, Case 3)

However, given the data overall emphasised the presence of strong family networks in socially deprived areas in this case, it is feasible that the reverse is true and patients in less deprived areas have weaker support networks. Several referrers, working in different settings, speak about the challenges of caring for patients who are socially isolated, through either rurality or not having family close by. In such circumstances, some community-based referrers say they would seek to put in social care packages but the lack of care agencies in the area led to some turning to the hospice as an alternative provider of care. One district nurse also has the impression that the hospice, if they needed to, would prioritise a patient living alone over one with lots of family support. This adjudication by healthcare professionals may generate more referrals in the less socially deprived areas. However, several participants also observe that it would be difficult to sustain home care for any individual living alone, and two referrers suggest they would seek to admit patients into a hospital or nursing home. It would be misleading to suggest that social isolation and family networks are definitively split along socioeconomic lines, or that these had singular relationships to referral. Participants – mostly those with specialist palliative care training – talk about some examples of social isolation in the more socially deprived areas and family circumstances in these areas to do with substance dependencies or mental health that influence referral decisions (see Theme 3). Nonetheless, the presence of family support networks is, from the perspective of many participants, the predominant characteristic they associate with more socially deprived areas in Case 3.

#### **Theme 2: Causes and consequences of 'getting on with it'**

All participants with specialist training in palliative care, as well as some generalists, speak about people keeping services at arm's length, often explicitly linking this to socioeconomic disadvantage and other times associating it with circumstances more common in socially deprived areas, such as mental health issues and alcohol or drug dependence. Referencing the stoical culture of many people living in the more socially deprived areas in this case, several participants frame distance as a positive thing for patients, observing that people "just get on with" (Sheila, Referrer Specialist Nurse) either caring for their relatives or themselves without intervention from healthcare services. A preference for privacy and family carers rather than strangers is also seen by some as a contributing factor to keeping services at arm's length. Referrers also speak about patients and families being mistrustful of professionals, perhaps because they feel let down by health and social services in the past:

People who have had very difficult lives before they come to us can have other issues that then the sort of acute illness can make it worse. Sometimes they haven't had the best experience with, say, other professionals. So, they're a little bit you know, if they've had a lot of input from social workers etc. they can be sometimes a little bit suspicious, a little bit anxious that people aren't necessarily got their best interests in mind, if that makes sense. (Francesca, Referrer Hospital Doctor, Case 3)

We have a lot, we have of a lot of mistrust in services you know if something's happened previously in a hospital...a lot of patients you will get that kind of confront when you arrive at a patient's house, 'well this is what's happened in the past', and you can see already that they're really angry and they don't want you to be there. (Polly, Referrer Senior Nurse, Case 3)

Other reasons given by referrers for why patients may keep a distance from healthcare providers include having less understanding and fewer expectations about what help is available. Two referrers emphasise the necessity for patients to recognise they have a need for healthcare or support in order to receive care, which may be less obvious to professionals if a patient is not proactively engaging with services. Having limited capacity within a healthcare service contributes to the belief held by one referrer with specialist palliative care training that patients have a responsibility to reach out if they want support, as staff cannot chase up every patient. Some see the potential for maintaining a distance to lead to a crisis and heighten distress for families in socially deprived areas, particularly if reality deviates substantially from what

patients and families expect to happen. It is feasible that the propensity to wait until a crisis coupled with less understanding about services may lead to some patients and families seeking input from urgent care services. One participant in an urgent care setting says that they often see end of life patients admitted to the emergency department, observing that patients from more socially deprived backgrounds "seem to have less well organised end-of-life care in the community [and] if in doubt, [they] go to A&E" (Chris, Urgent Care GP). Patients initially referred from the hospital in this case (17% of all referrals - see Appendix G) are statistically significantly more likely to be from more deprived areas than those referred by other services. It is feasible that this association is the result of patients from deprived areas attending hospital following a crisis, and their need for support at home becomes more apparent to themselves and healthcare professionals. However, the lower number of patients from socially deprived areas referred overall to the hospice home nursing service could also reflect barriers to making referrals to the hospice from urgent care settings; participants in these settings say they tend not have direct contact with the hospice service in this case.

### **Theme 3: Fitting untypical dying into a narrow hospice model**

Many referrers perceive the hospice nursing service as having quite a specific role in that they provided predominantly night-time support for families, alongside occasional day respite and other support. From the perspective of the community clinical nurse specialists in palliative care, who refer patients to hospice care, and hospice staff, their roles were distinct and different, although their sharing of a phoneline leads to some uncertainty amongst other (non-specialist) referrers about the relationship between the two services. Although pitched as a service for the last 12 months of life, most patients are initially referred to hospice home nursing within a month before they died. Many participants see the hospice home nursing as a service predominantly to help unburden family caregivers at home rather than providing specialist palliative care input directly for the patient. Some of the circumstances associated with socially deprived areas could feasibly make it more difficult for patients to fit into this model of care. Several specialist palliative care referrers and hospice staff describe houses where people are substance dependent or have mental health conditions as potentially unsafe for nurses required to spend long lengths of time working alone in a patient's home.

I think the problems come when drugs and alcohol are involved and then it can get very difficult because there might be some situations where it's too dangerous for us to go in or we have to go in in twos. And of course, that tends to happen more in socially deprived areas. (Connie, Hospice Senior Nurse, Case 3)

Some specialist palliative care referrers speak about trying to keep the hospice out of such situations, although a generalist palliative care professional describes needing hospice input if it was difficult to secure social care for people with mental health related aggression, either because of poor service availability or difficulties services had caring for people mental health related aggression. Patients with non-cancer conditions are also widely seen by referrers to be difficult to refer to the hospice home nursing because of uncertainty about their deterioration or, in the case of one GP talking about a patient with COPD, having symptoms not associated with typical dying:

...she had spells where she was reasonably OK and she had spells where it was really bad...

[hospice service] didn't really flag up on our radar as a result, because it wasn't typical dying.

She was suffocating with COPD and it scared her. (Susan, Referrer GP, Case 3)

#### **6.4.5. Summary of Case 3**

While not reaching statistical significance, the trend towards there being fewer hospice referrals in the most deprived areas in Case 3 may reflect a mixture of factors related to the presence of family networks, or that some characteristics found in deprived areas were not recognised as typical reasons for a hospice referral. While the overall proportion of referrals from hospital are low, this was the route into hospice care associated with patients in socially deprived areas, likely facilitated by the working relationships between hospice and hospital palliative care staff. However, the more restrictive model of hospice care coupled with the rurality of the catchment area arguably limits the way the hospice can support some patients and families with complex issues in deprived areas in this case.

## 6.5. Chapter summary

Each of the three cases in this study provides a unique picture of access to hospice care in socially deprived areas. While an in-depth comparison of cases is provided to the subsequent chapter, the within-case descriptions begin to reveal the nuanced way that the phenomenon of accessing healthcare in socially deprived areas is influenced by local factors. Each case clearly shares some similarities, most notably in the non-significant association between area deprivation and hospice referral rates. However, the three thematic analyses generate unique themes that portrayed the different overarching narratives to each case. The following chapter presents findings from the exploratory cross-case analysis, comparing these narratives and the evidence that underpins them. Building from this within-case evidence, the intent is to deliver a new set of broad themes that capture what the cases suggest, as a whole, about access to hospice care in socially deprived areas.

## Chapter 7. Results of cross-case analysis

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Each of the three cases in this study provides a unique perspective on the phenomenon of end-of-life care and hospice referrals in the context of social deprivation. Having examined each case individually, this chapter moves beyond the case-specific context to explore how these findings compare across the three cases. Incorporating evidence from all three cases, the results of this cross-case analysis convey what the data as a whole suggest about the relationship between socioeconomic position and access to hospice care, identifying factors relating to the specific case contexts and factors that appear common across the cases.

Data from 42 interview participants and statistical findings from each of the hospice referrals analyses contribute to the findings in this chapter. Participants include hospice employees and those who can refer patients to hospice care (Table 26), all of whom are involved in some way in the care of patients in the last year of life. Where findings relate specifically to hospice care or hospice referrals, it is made clear in the text. However, building on the within-case findings described in the previous chapter, the results presented here extend beyond just hospice referrals to participants' wider reflections on caring for patients in the last year of life in the context of social deprivation.

**Table 26: Distribution of participants across cases**

	Hospice staff	Referrers	Total
Case 1	4	7	11
Case 2	6	8	14
Case 3	2	15	17
Total	12	29	42

## 7.1. Summary

The lives and deaths of patients living in the socially deprived areas in this study are diverse and generalisations about them are often difficult. This is the sense conveyed by healthcare professionals providing end-of-life care to patients in socially deprived areas in the three cases in this study. While some feel comfortable talking about what they see as common experiences, others avoid speaking in general terms about socially deprived areas which they see as being home to diverse groups of patients. Instead they draw on experiences of caring for particular groups of patients within these areas and on experiences that, though sometimes rare or extreme, impact them professionally. When reflecting on providing care in the context of social deprivation, these participants speak about patients experiencing mental health difficulties, housing insecurity, substance use, isolation, or other specific issues. Participants' experiences of caring for these population groups are not assumed to be the general experiences of caring for patients in socially deprived areas where they work. Rather, they reflect how participants select certain examples when asked about providing end-of-life care in socially deprived areas. It may be that participants instinctively associated extreme situations with social deprivation, or that they turned to those extreme examples because of the difficulty they had talking in general terms. In making these observations, participants imply they are important for understanding access to hospice care in the last year of life in these areas. Cross-case differences in how participants identified and understood characteristics associated with social deprivation are explored in the first theme 'connecting with patients'.

In this study, participants reflect on their interactions with patients living in socially deprived areas in the last year of life, and what they do and could do to support these patients. Although rarely asked about the families of patients, many participants shared observations and experiences about supporting families in the context of social deprivation. When families were brought up, participants often perceived them to be experiencing similar socioeconomic circumstances to patients; an example of this appears later on this chapter in a discussion about mistrust of services. While this study is primarily focused on the care of patients, observations and findings relating to families are also acknowledged and incorporated into the analysis where relevant, recognising that participants considered this an important aspect to caring for patients in the context of social deprivation.

As well as describing some of the factors that can make it difficult ‘connecting with patients’ (theme one), participants share observations of service integration that appear to facilitate hospice services to ‘capture patients’ (theme two) from socially deprived areas at particular points as they transition around the healthcare system. While data from interviews dominate this chapter, in theme two the mixing of statistical and qualitative data is fundamental to this interpretation of findings. Those connecting and caring for patients draw on powers and resources to try to bridge gaps between patients and services and help them ‘get the best out of the system’ (theme 3). Participants also wrestle with professional responsibility and appropriateness in end-of-life care, reflecting on how ‘contradictions between ideal and realistic end-of-life care’ (theme 4) impact them and their understanding of good end-of-life care. Collectively, these themes demonstrate how participants simultaneously try to support patients living in areas of social deprivation whilst reflecting on the provision of that care within the confines of their profession and the wider healthcare system. This chapter begins by exploring participants’ understanding of how some patient characteristics influence the way they connected with services. It then considers how participants try to facilitate patients’ interactions with services, and finally how these experiences led participants to reflect on the goals of their profession.

## 7.2. Theme 1: Barriers to connecting with patients

Across the three cases, participants discuss characteristics they associate with some patients in socially deprived areas that could plausibly create barriers to establishing a dialogue or connection between patients and healthcare professionals. While not always presented as problematic or something for professionals to overcome, these characteristics seem to prevent connections in the physical sense, by limiting face-to-face interactions, and in the relational sense, by influencing communication between professionals and patients. Participants describe patients not wanting to let healthcare services into their home, not proactively seeking healthcare services, or drawing only on large local family networks for support. Others suggest that unmanaged anxiety in the wider family unit, anger, and the impression of being mistrustful of services could be problematic for establishing an effective dialogue with patients and their families. Without the perspective of patients and families to draw on, it is difficult and inappropriate to try to explore the sentiments underpinning patient behaviours. What the accounts can show is how professionals understand and explain to themselves the characteristics or behaviours they

observe. The idea of ‘connecting with patients’ is explored by focusing on two findings: the locally driven understanding of patient behaviours; and how participants understand and navigate experiences of mistrust.

### **7.2.1. Localised barriers to making connections**

While the socially deprived areas of each case are home to patients living in different circumstances, participants tend to emphasise certain characteristics as being particularly representative of their area. In the first case, participants highlight the prevalence and impact of mental health illness. In the second, they speak about socially isolated transient populations alongside patients with large local networks of families. In the third, the emphasis is primarily on patients with local networks of self-reliant families. When participants discuss these characteristics, they draw on their understanding of cultural, social or organisational history to the area to provide context to the behaviours they observe. While this study was not designed to capture detailed historical context, these observations draw attention to the way that experiences at the end of life, and how participants’ associate this with social deprivation, can feel locally driven. In Case 3 the suggestion that patients have access to family networks coincides with the belief that people tend to stay put in the area, which is geographically isolated from other regions. One participant describes families having historical ties to isolated pockets of localised industry:

You know, they're only there because there was a mine at one time. I mean up and down that R1 I think at one time there was 250 small mines so I still look after a lot of families that still have, or were involved in mining. There's not as many people travel away. I think there are not, many families still don't have cars and that sort of thing, you know... (Sheila, Referrer Specialist Nurse, Case 3)

Sheila describes the local population as family-orientated but geographically isolated, partly because of their economic circumstances (“still don’t have cars”). Contextualising this observation with reference to the now defunct local mining industry, she emphasises a local experience that, while it may be relevant beyond that case, is not raised in Cases 2 and 3. In contrast to Sheila’s depiction of her area, participants in Case 2 talk about large populations of socially – not geographically – isolated people living alongside those with access to family networks. While this area has pockets of deprived and affluent areas within

a coastal region, several participants refer to one large town when describing the nature of social deprivation within this case. Observations about socially isolated populations are sometimes tied to the belief that people move in and out of, and around, the area. Val describes this in context to the attraction of the area, a seaside holiday town, to move to:

And we're a holiday town as well. So, we don't just get people living here. We get so many people, it's on the bucket list, to come to die... you get a lot of people living in bedsits and living on their own... Yeah and we have a lot of elderly. So, a lot of people, like I said before, come to die here. But they might have lost one of their, their other partner in the past, and there's nobody left. So, they'll, they are basically on their own. (Val, Hospice Senior Nurse, Case 3)

This depiction of a transient and potentially insecure population is in stark contrast to Sheila's description of an apparently more static population in Case 3 where 'not as many people travel away'. Participants in Case 1 offered a further perspective. While participants do not refer to a social history particular to that case, there is a consensus about how the historical organisation of healthcare services had contributed towards the end-of-life experiences of those living in the more socially deprived areas. Several participants believe palliative and end-of-life care patients in these areas are disadvantaged in their access to mental health services because of how services had been organised in the past. Adi describes the impact she saw this having on some of her patients:

... it probably took me about three years to think what is different here because there are only small pockets [of deprivation] but it is an awful lot of mental health problems. When the mental health institution was closed down they were all moved to the area which was all the guest houses... before the palliative diagnosis they've got extreme complex psychological issues that have never been addressed, never been resolved, and then you've got that death diagnosis on top of that and that actually exacerbates everything that's happen in the past. It's all there. They are very difficult to symptom management because they, we don't have level 4 psychological support in the area. (Adi, Referrer Specialist Nurse, Case 1)

Representative of a broader emphasis in each case, Sheila's, Val's, and Adi's accounts highlight the potential for areas that may appear socioeconomically similar on paper to differ in the nature of the

deprivation experienced by people living there. Participants perceive the nature of social deprivation experienced by patients in each case to be partly generated by a social or organisational context specific to that area.

Different characteristics appear to influence connections between patients and professionals in different ways. Having a large family network, for example, is in many instances associated with patients not making as much contact, and sometimes none at all, with services. In areas where it is common for patients to have strong family support, as is the case in many areas of Case 3, the family are sometimes seen as particularly private or reluctant to accept support. Some hospice staff participants in Case 2 suggest a similar pattern when discussing how patients with large family networks in their area sometimes use their services. Equally, however, there is evidence of patients who are socially isolated and living in socially deprived areas also avoiding services or fluctuating in and out of them. This sense of fluctuation is particularly present in interviews with participants in Case 2, where there is an awareness of a large population of transient or substance dependent patients whose lives may, as some describe it, appear chaotic. In contrast, while similar issues were present in Case 1, the emphasis on caring for patients and family members with potentially unmet mental health needs is portrayed not as an issue for establishing physical contact but for establishing effective communication and building a relationship during interactions. While these are just some of the ways in which these characteristics may influence how patients connect with services, or appear to, they reiterate the importance of local context. How healthcare professionals understand the issues that can make it difficult establishing a connection with patients may stem from their understanding of the characteristics associated with the socially deprived areas in their region.

#### **7.2.2. Navigating mistrust and expectations**

Having contrasted some of the characteristics specific to each case, this section of the analysis moves on to consider commonalities between the cases. This theme conveys how participants labelled the attitudes and behaviours of some patients and families in interactions they had with professionals. This focuses on two specific characteristics that were identified in different ways by participants across the cases: mistrust and expectations of care.

While mistrust holds relevance in healthcare beyond social deprivation, participants across the three cases suggest it is a sentiment underpinning several of the characteristics they observe among some patients in more socially deprived areas. In their efforts to establish a connection with patients, many professionals speak about navigating mistrustful interactions, which they contextualise with reference to patients' wider experiences of formal support services. Some of the strategies participants employed in response to mistrust are detailed in a later theme (getting the best out of services). This theme first draws together data on participants' perception of that mistrust.

Across the three cases, there is a pattern to these interpretations. Many participants perceive some patients, and families, in socially deprived areas being mistrustful of services. Mistrust can be found in accounts of patients and families not sharing information about substance use, blaming health services for late diagnoses or poor treatment outcomes, scepticism that hospice services could help them, expressions of anger, and not allowing uniformed professionals into homes. Here, Becky, a hospice staff member in Case 2, describes mistrust as a big issue in the area where she works:

Massive mistrust yeah and sometimes they do just disappear off and we can't see them and, you know, you just have to accept that erm they will just say I've had enough. Why would you trust someone? You've been on the streets since 12, you know, he was in care before that, they're not going to just 'oh you're the nice palliative care doctors' you know, erm, so yeah you know we have big issues and we try our best. (Becky, Hospice Senior Doctor, Case 2)

Like Becky, others speak about trust and mistrust or use word such as "standoffish" (Val, Hospice Senior Nurse, Case 2) or "suspicious" (Francesca, Referrer Doctor, Case 3) to convey how they interpret patients' apparent reluctance to connect with services. Although drawing on different terminology, these accounts convey a similar sentiment to the mistrust mentioned by Becky and others. They suggest participants were perceptive to the distance between themselves and their patients and how it could make it difficult to initially establish a connection with them. In her interview, Becky prefaced the statement above by describing a patient's reluctance to share information about their medication for fear she would take it from him, which led to her forming an impression of a patient being mistrustful of her. While presenting this as the immediate cause of the patient's apparent mistrust, she goes on to reflect about patients' broader life experiences. Becky interprets mistrust of herself and of palliative care services as

an understandable consequence of earlier life experiences, contextualising one patient's behaviour within their experiences of institutional care and homelessness in the decades before arriving at the doors of a hospice service.

Others also took a longer view on what generates mistrust in their services at the end of life. Many participants acknowledge that mistrust of services towards the end of life is driven by a recursive experience of social disadvantage and of accessing support over a long period of time and across multiple institutions. Mistrust is particularly seen to stem from patients' and families' prior, and reportedly poor, experiences of health and social care services. In some accounts, this can be inferred from the situation that participants describe, for example a patient not allowing uniformed professionals in their home. Adi, a specialist palliative care referrer in Case 1, is more explicit in linking patients' previous experiences of accessing formal services to their interactions with her:

...we've got a home massage service for the palliative patients who are too unwell to come [to the hospice] and again I will not offer that until I find out if she's got availability because if she hasn't got availability what's the point in talking about a service that's not there for these people who have got mistrust in services already.

Interviewer: Do you see that a lot?

Oh, an awful lot. We had, T1 especially, before GP1-group took over the practices, there were two GP practices that had very, very part time partners only and the rest of the time was actually manned by advanced nurse practitioners so there was an awful lot of undiagnosed disease, late diagnoses. So, you were dealing with that anger at not being heard, not being seen, getting a disease that probably would not have made much of a difference being seen earlier but, in their mind, if they had been diagnosed earlier, they had the signs, they had the symptoms, they would have had a different outcome. (Adi, Referrer Specialist Nurse, Case 1)

Adi describes mistrust being generated from apparent poor access to primary care in T1, one of the most socially deprived towns in Case 1, and expressed by patients in blame and anger at services. Consequently, she does not offer services that do not have guaranteed availability, for fear this would

generate further trust issues. Adi is not alone in linking these experiences to patients' earlier encounters with services; others suggest that patients avoid services after feeling they had been put "on the back burner" (Polly, Referrer District Nurse, Case 3) or are sceptical of hospice care because "no one helped me in the past" (Val, Hospice Senior Nurse, Case 3). These prior experiences of care are seen to lay the foundation for subsequent interactions with healthcare professionals at the end of life.

These accounts coincide with broader evidence in this study of reportedly poor access to services in socially deprived areas. Participants describe patients having trouble making and attending appointments at services where there are fewer staff, higher workloads and high demand for primary care services, for example. Others recognise the difficulties some patients living in disadvantaged circumstances had prioritising appointments with services amid other needs in their life. While all examples of poor access were not linked by participants to difficulties building patient-professional relationships in the last year of life, it is feasible that such experiences – as Adi suggested – could lead to a more mistrustful environment for patients.

Poor access could feasibly contribute to mistrustful and angry interactions. Simultaneously, mistrust and anger can lead to subsequent issues with access. Kate, a hospice staff member in Case 2, describes part of this cyclical process some patients find themselves in:

I suppose people in more affluent areas tend to be slightly better educated and certainly more vocal and articulate and actually able to say in a way that people understand I'm struggling. I think people do say it in the socioeconomically deprived areas but probably in ways that don't trigger a response, they'll often get angry, and they'll often lash out at some, we often saw that they would often lash out at a service because it wasn't doing what they wanted it to do and that anger would then mean that service was pulled out rather than finding out what it was they really needed. (Kate, Hospice Senior Doctor, Case 2)

Seen together, Adi's and Kate's accounts suggest that mistrust, anger, and access have the potential to become locked into a recursive process of receiving or not receiving care. Becoming involved in the later stages of a patient's life, the nature of end of life and hospice care professionals' interactions with patients may be determined by encounters with services long before a patient's illness became advanced.

Additionally, when faced with potentially challenging interactions, service providers may be ill-equipped or unwilling to respond to expressions of mistrust and anger.

Alongside the pattern of mistrust evidenced in many participants' accounts, there were observations of patient-professional interactions of a slightly different nature. Several participants described some patients in socially deprived areas appearing to have low expectations of care and of their health in general. Carol and Sheila, from Cases 2 and 3 respectively, share their perspectives on expectations and social deprivation:

...if we use T4 as an example, the expectations are greater so people expect you to respond as and when they want you to respond...whereas in less affluent areas, they are just grateful for whatever they get (Carol, Hospice Senior Nurse, Case 2)

I think if I'm honest, if I'm very middle class about it, they've got low expectations. I have less problems with my patients than one of my colleagues who lives in C1.... it's about lifelong expectations. 'Well I've had a good life, you know, what do you expect, I'm 70' and I'm thinking god that's young... (Sheila, Referrer Specialist Nurse, Case 3)

The suggestion of gratefulness among people in "less affluent areas" is not an observation unique to Carol, and neither are comparisons of expectations across different socioeconomic areas or population groups. While patients in socially deprived areas are not always portrayed as having lower expectations of care, the suggestion by several participants that this was the case offers a different angle to the arguments regarding mistrust. These accounts of lower expectations and gratefulness, reflected in the excerpts from Carol and Sheila's interviews, convey a less challenging interaction to those where participants felt mistrust or suspicion was present. Drawing attention to the different accounts here demonstrates the diversity of experiences when providing care to populations within similar socioeconomic areas. However, apparent expressions of gratefulness and lower expectations may reflect similar difficulties with lifelong access to services. Carol's suggestion that some patients are "just grateful for whatever they get" speaks to the point about patients struggling, for a variety of reasons, to access care prior to interacting with services at the end of life. People are likely to process these

experiences in different ways, with consequences for their interactions with service providers later on in life and how healthcare professionals interpret the sentiment underpinning them.

#### **7.2.3. Summary of theme**

The participants who contribute evidence to this theme come from similar positions of wanting to connect with patients. They discuss how patient characteristics, some of which appear driven by local conditions, can deter a connection from being established. While this is not always portrayed as a negative characteristic, they reflect on how mistrust appeared to underpin some patient behaviour. Mistrustful interactions are linked to broader experiences patients may have had interacting with health and social care services throughout their lives. While this theme touches upon the potential for this to impact services received at the end of life, it does not explore how difficulties connecting with patients may have consequences for hospice referrals. At a first glance, the idea that some patients in socially deprived areas keep service's at arm's length – either physically or relationally - does not tally with the lack of statistically significant association between social deprivation and hospice referral rates found overall in each case. The subsequent theme examines the evidence on hospice referrals, given the findings relating to patients' interactions with healthcare professionals described above.

### **7.3. Theme 2: Capturing patients at moments of vulnerability**

The previous theme described the ways in which characteristics participants associated with social deprivation could make it difficult to establish a connection between patients and professionals. Building on this argument, the evidence outlined in this section shows how some patients from socially deprived areas may seek healthcare at moments of vulnerability following a crisis or time of heightened stress or emotion. The seeking of healthcare at these moments coincides with a flexibility in each hospices' remit that helps facilitate referrals. Drawing on data from both the analyses of hospice referrals and from interviews with some participants, this section suggests how these two factors relating to patient vulnerability and the hospices' approach combine to help generate referrals of patients from more socially deprived areas. This allows the hospices to make contact or, as one participant describes it, to 'capture' patients as they flow in and out, and around, the healthcare system.

While there is no strong evidence in this study of a relationship between social deprivation and hospice referrals overall, the analysis of patient data in each case suggests some pathways into hospice care appear more likely for those living in the more socially deprived areas. Before exploring the experiences of participants in relation to these pathways, it is useful to revisit the statistical findings regarding referrals. The referral pathways, and their association with social deprivation, are not identical across the three cases. In the first case, patients initially referred to the day hospice service tend to live in the more socially deprived areas of that catchment area than patients referred to the inpatient and hospice at home services (Table 27). In Cases 2 and 3, the pathway into hospice care for patients living in socially deprived areas is not strongly associated with one service, but rather with who makes the referral (Tables 28 and 29). In both cases, hospice patients referred via a hospital tend to be living in more socially deprived areas than those referred via community services. These results are shown with the related estimates and measure of statistical significance in Tables 27-29, followed by qualitative evidence from participants that explore these findings. Concerning referrals to day hospice and from hospital respectively, these pathways may initially appear unconnected. Examining this in context of data from interviews, however, suggests that referrals made through these routes could partly be a consequence of capturing patients and families who hold off from seeking and accepting services until a time of heightened need.

**Table 27. Change in deprivation rank by initial service received (Case 1)**

Descriptive statistics (deprivation rank)					Univariate analysis	Multivariate analysis (with age)
	Mean	Median	.25	.75	Change in deprivation rank <sup>1</sup>	
Day hospice	74	73	28	122	-	-
Inpatient hospice	80	81	38	122	6.51*	6.96*
Hospice at home	80	82	37	126	6.77*	5.97*

\*p value < 0.05.

<sup>1</sup>When comparing patients in different characteristic groups. A higher rank (positive value) corresponds to coming from less deprived areas. Values for services are when compared with patients referred to day hospice.

Table 27 compares patients referred to day hospice in Case 1 with those referred to hospice at home or inpatient care in terms of the deprivation of the area where they live. It shows that patients referred to hospice at home or inpatient care in Case 1 tended to be from less deprived areas than those referred to day hospice. This is because a lower rank means patients using that service were on average from more deprived areas. Therefore, an increase in deprivation rank (a positive value in the two columns furthest on the right in Table 27) means patients receiving inpatient and hospice at home care were on the whole living in less deprived areas than those receiving day hospice. Tables 28 and 29 can be interpreted in a similar way, although for the variable of interest is who referred patients rather than the service they received.

**Table 28: Change in deprivation rank by referrer group (Case 2)**

Descriptive statistics (deprivation rank)					Univariate analysis	Multivariate analysis (with age)
	Mean	Median	.25	.75	Change in deprivation rank <sup>1</sup>	
Hospital	103.2	102	56	151	-	-
GP surgery	108.7	111	62	153	5.61*	5.97*
Community	93.7	83.5	52.8	142.8	-0.49	-10.05
Internal	96.4	99	44	140.5	-6.75	-4.37
Out of hours	107.7	107	64	151	4.51*	-0.89
Other	144.8	151	118	175.8	41.66*	42.03*

\*p value < 0.05. <sup>1</sup> When comparing patients in different characteristic groups. A higher rank (positive value) corresponds to coming from less deprived areas. Values for referrers are when compared patients referred from hospital.

**Table 29: Change in deprivation rank by referrer group (Case 3)**

Descriptive statistics (deprivation rank)					Univariate analysis	Multivariate analysis (with age)
	Mean	Median	.25	.75	Change in deprivation rank <sup>1</sup>	
Hospital staff	43	42	18	68	-	-
Clinical nurse specialists	50.8	54	25	74.75	7.8*	7.63*
District nurses	51.1	55	32	70	8.05*	7.04*
Informal	53.1	57	37	74	10.09*	9.11*
Internal	63.3	58	51	73	20.32	20.07
Other (non-HCP) <sup>2</sup>	51.6	35	35	86.5	8.59*	7.57*

Other (HCP) <sup>2</sup>	47.5	50	21	73.5	4.48	3.83
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\*p value < 0.05. <sup>1</sup>When comparing patients in different characteristic groups. A higher rank (positive value) corresponds to coming from less deprived areas. Values for referrer are when compared with patients referred from hospital. <sup>2</sup>HCP= Healthcare professional

In addition to the earlier evidence highlighting difficulties connecting with patients, some participants reflected on the moments when some patients appeared readier to accept input from healthcare professionals. These moments sometimes follow a change in how patients recognise and express their potential need for care. Jane, a GP in a socially deprived neighbourhood in Case 2, where referrals from socially deprived areas were associated with the hospital, sees this shift occurring for some of her patients when they are in hospital. She describes the effect of this on some patients' readiness to talk about hospice:

And often they sometimes, especially if they are an inpatient in hospital, they are often more, I suppose, because, I don't know how to say, they're probably in more vulnerable states. They're often perhaps more amenable to having that conversation... because often it's around the time when they've just been given some bad news, emotions are usually running quite high if they're in hospital, and they'll often take it at that sort of stage. (Jane, Referrer GP, Case 2).

Jane suggests that some patients are more “amenable” to talking about hospice in hospital than when they are under primary care. She ties this to the likelihood of a patient in hospital experiencing a change in their illness, or in their understanding of it, and an increased vulnerability. This depiction of interactions in a hospital setting contrasts to other moments in Jane’s interview where she speaks about some of her patients finding it difficult to engage with primary care services in a proactive way. While in the quote above Jane does not refer specifically to patients in socially deprived areas, she speaks about a pathway into hospice care more likely to be taken by patients in those areas. A similar referral pattern was found in Case 3, where social deprivation is also associated with referrals from hospital settings to hospice care. While no participant in that case speaks about patients potentially being more amenable to having conversations in hospital, one GP describes emergency hospital admissions being triggered by minor changes that may be “the final straw” that leads to patients or families feeling unable to cope (Chris, Referrer GP, Case 3). The same participant observes that some patients experiencing socioeconomic disadvantage who access hospital care appeared to have more poorly organised end-of-life care in the community. It is feasible that such patients may end up seeking hospital care in moments of vulnerability.

Turning to Case 1, where hospice referrals from the most socially deprived areas of that case were associated with day hospice, another account from a GP describes the context to those referrals:

...there is a lot of anxiety which makes their breathing worse anyway which makes them see you more... So as a generalisation you tend to find the higher socioeconomic groups are more empowered to say this needs sorting out, you need to help me with my health. Whereas, those from lower socioeconomic groups tend to be more of a 'it's not working, why are you not helping, why are you not working it out', but not so much empowered, more of a kind of 'I've got this problem, you need to fix it'...you end up seeing [patients who are socioeconomically disadvantaged] a lot more because, because of their, as I said, their difficulty understanding their disease and prognosis and what to expect to the disease. So, you end up seeing them a lot. So, as a GP, it kind of boils down to well how can we minimise how much you come see me. The day hospice is very good, we've had some good experience, let's send you for some of that... (Jonathan, Referrer GP, Case 1)

While Jonathan uses different terminology to Jane, and describes interactions in a different setting, he also reflects on patients' emotional states. The anxiety and disempowerment triggered, from Jonathan's perspective, by poor understanding speaks to a vulnerability among patients that Jane also conveys. Jane speaks of patients' emotions running high after changes in their clinical situation or in their understanding of it. The patients Jonathan describes appear to be more amenable to a hospice referral because their anxiety around unexpected symptoms and difficulty understanding the illness. While these accounts differ in some ways, they describe patients seeking input from healthcare services at a moment of heightened emotion. Patients are seen to seek care not because they are pre-empting their needs but because they feel uncertain or stressed following a, sometimes unexpected, change in condition.

The observations about patients possibly seeking or accepting input at time of apparent emotional vulnerability sits within the wider evidence base of patients not connecting with services, potentially until a crisis occurs. Carol, a hospice staff member in Case 2, brings together these corresponding patterns of accessing and not accessing care, and their potential relevance to crisis interventions, when she states:

...I think there is something around, erm, patients from kind of less affluent areas actually accessing GP practice. And actually, it becomes more of a crisis intervention as oppose to a, a relationship in which you know our community team as an example could support the patient in many different ways. (Carol, Hospice Senior Nurse, Case 2)

While crisis referrals were not associated with social deprivation by all participants, several spoke about difficulties, or a reluctance, to connect with services coinciding with patients seeking input when they are no longer able to cope. Polly, a district nurse in Case 3, in response to a question about care in socially deprived areas, speaks about the circumstances in which some her team end up connecting with patients:

And when they, kind of a lot of our patients that we see they try and keep off our radar quite a lot. So, we go in kind of at that point where they've really not been able to cope. So, we have to deal with a large amount of things at the end of life stage... (Polly, Referrer District Nurse, Case 3)

Although she does not use the word crisis, Polly conveys a similar sentiment to Carol when she speaks about dealing with lots of things but with little time. Others spoke about the fire-fighting or fire-dampening nature of their work with some patients in socially deprived areas who struggled to connect with services in a timely and optimum way. Some participants accept that to pick up some patients they have to allow them “to be admitted so they can capture them via hospital” (Val, Hospice Senior Nurse, Case 2). Building on earlier evidence, this draws attention to how participants see the consequences of not connecting with patients. Val and Polly’s accounts suggest that the way some patients flow around the health and social care system means they are more likely to connect with services at moment of crisis. In many of these accounts, the accessing of services by patients in reaction to an unexpected change in condition or heightened emotions is portrayed as an expected consequence of patients’ broader experience of connecting with services throughout their illness.

That patients may recognise a need for support and seek input is probably insufficient on its own to facilitate referrals to hospice care. The times when, statistically, social deprivation is significantly associated with differences in referral pathways appears to be when patients’ recognition of need for care

coincides with a flexibility in the hospice's scope and in how care is provided. For example, there is evidence of the hospices' broadening their scope to become more inclusive of a range of patient and healthcare professional needs at times where patients in socially deprived areas appear more likely to receive a referral. Changes to the day services in Case 1 accommodates patients with conditions other than cancer and who are not necessarily in the last months of life. The restructuring of support also, according to hospice staff, allows more patients to flow through day hospice than have done in previous years. In Case 2, some spoke of the hospice accepting referrals of patients from the hospital with less complex needs, recognising the limited capacity in the local hospital to lead on palliative care in that setting. The hospital-based hospice service also maintains a presence on hospital wards and, according to hospice staff, is seen as appropriate for patients other than those with cancer. The hospice in Case 3 has arguably fewer opportunities to broaden the services they offered, given the lack of physical space to provide day or inpatient care. Nonetheless, their input into the care of hospital patients goes beyond the usual provision of home nursing to include support for hospital discharges and sitting with patients on inpatient wards. While these are not the only examples of the hospices demonstrating adaptability and flexibility, the broadening of their scope in these ways feasibly facilitates the referral of patients who, for whatever reason, do not initially access hospice care via primary care (Cases 2 and 3) or do not initially receive hospice at home or inpatient care (Case 1). In these cases, then, the route by which hospice patients from more socially deprived areas tend to initially receive hospice care may, to some extent, be an unintended consequence of the way in which a hospice service fits within to the wider healthcare system.

Given that some patients may hold off from connecting with services until moments of heightened vulnerability, it is plausible that such patients may access hospice care closer to death. This is suggested by one hospice staff member in Case 2. While this might be true, this does not translate to patient populations in socially deprived areas being referred any later to hospice than those in other areas. In each case, there is no statistically significant difference in how late patients were referred to hospice care depending on the deprivation of the area where they lived. This may mean that those whom participants described as accessing their services at a point of crisis are a small population who would not be picked up in the analysis of late referrals at an area level. Alternatively, the crises generating contact with professionals may not necessarily be triggered when patients are in the last few weeks of life. As

participants do not discuss these potential explanations, it is difficult in this study to explore the discrepancy between some participants' observations about patients delaying contact with services and no difference in the timing of hospice referrals between people living in different areas.

#### **7.3.1. Summary of theme**

Some patients in socially deprived areas may connect with services at moments of vulnerability following a, perhaps unexpected, change in condition or crisis. Pulling together evidence from referrals data and interviews, this characteristic appears to coincide with a flexibility in the hospices' remits that facilitates them capturing patients presenting at different points in the healthcare system. The interaction of these factors may explain why some referral pathways into hospice care are associated with patients living in more socially deprived areas. When seen alongside the previous theme, this evidence presents a holistic picture of how patients flowed around the system. It is plausible that difficulties connecting with patients in some circumstances, such as in primary care or because of low levels of trust in services, may lead to connections being made in other settings or with other providers. This speaks to the recursive nature of accessing services, whereby earlier interactions – or an absence of interactions - feed into future ones. Participants differ in their apparent awareness of this process but the ability of hospices to capture patients at different points in the healthcare system appears to facilitate referrals of patients in more socially deprived areas.

### **7.4. Theme 3: Getting the best out of services**

Having explored how and when participants connected with patients, this part of the analysis moves on to consider how healthcare professionals negotiate with and for patients, using time and other assets afforded them by their position in the healthcare sector. These negotiations surface in accounts of interactions with patients and other health and social care professionals as participants navigate issues to do with capacity and appropriateness in the context of social deprivation. Participants working in different settings across the three cases reflect on their role and ability to help patients in socially deprived areas get the best out of services in the last year of life. This evidence forms two sub-themes: the first explores participants' attempts to 'bridge the gap' between patients and service providers; the second

looks specifically at how participants draw on ‘time and capacity’ as resources, reflecting on what this means for hospice referrals.

#### **7.4.1. Bridging the gap with and for patients**

Many participants describe ways in which they support patients to get the best out of a healthcare service, whether that is in primary care, hospice care, or a different setting. This involves bridging any gaps – physical and relational – between patients and other support services, and between patients and themselves as professionals. While interactions with patients in socially deprived areas may vary, participants try to move towards a goal of shared understanding about what services can and cannot do. Alongside individual power afforded professionals by their position in the healthcare system, hospices can potentially harness organisational power if the model of care facilitates it.

Participants’ observations about a gap in understanding between themselves and patients, or families, are often followed by examples of what, as healthcare professionals, they can do to try and close that gap. When responding to attitudes encountered among some of her patients in socially deprived areas, Sheila, a referrer in Case 3, sees herself entering a negotiation:

I see ‘well lass what can I do? You know, there’s nowt I can do about it so let’s just get on’....

I do a lot of work about what we can do, to settle them and make them comfortable...how are we going to manage things and we sort of you know negotiate a way forward if you see what I mean. (Sheila, Referrer Specialist Nurse, Case 3)

While elsewhere in her interview Sheila presents a “get on with it” attitude as a positive attribute of many of the patients she works with, the quote above suggests she is conscious that patients may not instinctively understand how services could benefit them. Sheila’s positioning of her interaction with patients as a negotiation highlights a common observation among participants about having to work to narrow a gap between their professional perspective and that of a patient, or a patient’s family. Her attempts to tentatively persuade patients to accept more support by explaining what she can do for them are mirrored in other accounts. Some participants speak about needing to demonstrate their usefulness to

patients. Hospice nurse in Case 2, Val, for example, describes obtaining Macmillan financial grants as helpful for building relationships with mistrustful patients.

While Sheila's and Val's accounts reflect efforts to raise expectations of services, there were also some – although fewer – accounts of participants trying to lower expectations. Adi, a referrer in Case 1, perceives expectations from some patients to be high in the socially deprived areas where she worked. Adi, and some other participants, describe explaining to patients and families what services do not have the capacity to do. This is in stark contrast to observations in other cases of participants trying to persuade patients that services can do more for them. Although they involve different discussions, attempts to lower expectations have a similar goal to those trying to raise them: to arrive at what participants see as an appropriate understanding and use of their services by patients. To aid this, Adi draws on her skills to try and improve resilience among some of her more expectant and dependent patients. In a similar way to Val's tacit understanding of grant money being accepted in exchange for trust, Adi offers patients skills in exchange for less dependency on services. While participants do not always explicitly use the language of negotiation and exchange, it was a sentiment underpinning many accounts of finding ways to help patients get what they could out of a service.

One skill some participants offer patients is an ability to navigate health and social care systems. Whereas some patients and families, particularly those in disadvantaged socioeconomic circumstances, appear to face difficulties either knowing where to go or how to establish contact with services, healthcare professionals are able to use their position of authority and knowledge to help steer some of patients through the system. Alongside the ability to refer patients, some participants take on advocate roles for those who were struggling to access resource-poor services. This includes, for example, persuading GPs to carry out a home visit for patients who may be too ill to attend the surgery:

I have people that have, you know, terminal cancer diagnoses, that can't get in and see their GP and the GP at best will do a consultation over the phone when they need seeing... So very often we intervene and we ring the surgeries and we ring and speak to the GPs and say look I need you to go out and see this patient, I'm really concerned. (Louise, Referrer Specialist Nurse, Case 2)

Louise's authoritative position allows her take on the role of advocate for her patients if deemed necessary. She sees her position as a healthcare professional and a specialist in her field as providing her with more persuasive power than that held by her patients. Her experience is reflected in other accounts, particularly in Case 2. Another participant speaks about being a "middle man" that "stands in the gap" between patients and some GP surgeries (Rachel, Referrer District Nurse, Case 2). This notion of standing in the gap emphasises that participants were not only negotiating a way forward with patients and families but also with other professionals. While healthcare professionals may do this for any patient struggling to access other services, the evidence of poorer access to primary care in socially deprived areas in this study means it is feasible this is an action taken more often for patients in those areas.

The authority participants have to stand in the gap between patients and services as an advocate is not only predicated on their position as a healthcare professional but also on their relationship with other professionals. Participants frequently discussed the nature of their relationships with other professionals involved in the care of patients in the last year of life, both inside and outside healthcare. One participant, for example, working in a socially deprived area describes her ability to "pull strings" (Adi, Referrer Specialist Nurse, Case 1) for patients being strengthened by having built up trusting relationships with other healthcare professionals such as district nursing teams. While important for all patients, establishing and maintaining relationships across multiple services arguably holds greater relevance for patients with social needs associated with living in a socially deprived area. In addition to relationships with other healthcare providers, participants support patients living in complex social circumstances describe liaising with a range of support services, included social services, housing and homeless services, financial benefits advisors, drug and alcohol support, mental health care, and police. While emphasising the ability of some patients and families in socially deprived areas to manage well with minimal input from services, when complexities do arise, participants either sign-post patients or draw on those networks for support with providing care.

Alongside accounts of healthcare professionals drawing on their personal authority to help patients navigate systems, others discuss the specific role and ability of hospices. One hospice staff member reflected on the power provided by the name and brand of the organisation, which was seen to open doors:

And I do think, whether I'm saying this in the right, vein or not, that actually [hospice] opens doors because it's a hospice, it's a charity. And it does push people to do things faster, because people, you know, people in community, as in, if we look at people being rehoused we'd hope that saying they are under [hospice] would push that a little bit faster because they would know that time's short so I do think that other health professionals use us for that and that often isn't a bad thing but that isn't what we do. (Val, Hospice Senior Nurse, Case 2)

While Val provides a thoughtful reflection on the potential of power to extend beyond that of an individual and to an organisation, few other participants offer this perspective. This may have been partly a consequence of the breadth of services offered by the hospice Val worked for, which differs to the hospices in other cases. Val works in the largest of the three hospice organisations in this study. Like Val, other staff members also say they are regularly involved in supporting patients – alongside district nursing teams – with issues relating to housing and other social needs. One of the teams under that hospice's umbrella includes the clinical nurse specialists (CNS) in palliative care. The CNS team are responsible for supporting patients with a broad range of complex needs including those relating to social and psychological concerns. In contrast, the CNS teams in Cases 1 and 3 work closely with the hospice but, at the time of the study, fall under the remit of the NHS and are considered referrers. The community-based services in those hospice organisations tend to focus on providing practical support or respite care for patients and families in the last few weeks and months of life. This different approach to integrated care may account for those hospices taking less of a role in responding to needs relating to housing or finance, for example, which may be identified before the last few weeks of life. Consequently, this may lead to less reflection on the potential power of their organisation's brand to influence this aspect of care.

#### **7.4.2. Drawing on time as a resource**

As with all healthcare professionals, one of the resources those caring for patients at the end of life can draw on is time. Whether professionals have time to care for patients at the end of life is often related by participants to organisational resources and capacity, seen as a consequence of issues to do with clinical recruitment, financing, and changing population health needs. Some participants suggest that supporting patients in socially deprived areas can require more time and input, an observation coinciding with the perception of providers in those areas having less time and fewer resources to do so. Participants differ

in their understanding of how capacity and resource gaps in the wider system can influence hospice referrals, and in beliefs about how appropriate it is for hospices to respond to these resource gaps.

When discussing their input into the care of patients in socially deprived areas, several participants discuss the time and resources sometimes required to support some patients. This includes needing more time to build understanding and trust or to help patients and families get the facilities needed to provide care at home, which can lead to lengthy and multiple visits. Adi outlines what is involved in providing care to some of her patients in these areas:

People can't understand why we can't do more. Well when you actually think about some houses that you go in and the state it's in you can be in there two and half, three, hours and only actually brush the surface. You then have to come away, you have to write all of that visit up. You then have to refer here there and everywhere ... and you haven't actually achieved much on your assessment [laughs] because you've just been dealing with the situation rather than actually going in and assessing the whole, so then you're going to have to go back to find out more. To find out did all these people you get in touch with, did they get in touch with you. What are the symptoms now? What are the issues now? Sometimes you've got to dampen down that fire to start with the next level. (Adi, Referrer Specialist Nurse, Case 1)

Adi describes the time required to care for patients extending beyond the initial consultation to include connecting patients with other services and tackling multiple issues over consecutive visits. This reflects other accounts where participants carry out multiple visits and, generally, provide more input for those who, as Rachel (Referrer District Nurse, Case 3) put it, "might not have the facilities to cope as well". The facilities Rachel refers to include having very little space in a patient's home to put in equipment or not being able to afford to top up the gas and electric metre; others also refer to patients not being able to afford soap, milk or provide a basin for hot water. Helping to source and provide facilities to patients, while not necessarily complex or complicated, is nonetheless time-intensive and may involve liaising with teams beyond those typically involved in specialist palliative or end-of-life care.

The suggestion that more time and input is needed, generally, to support patients in socially deprived areas tends to be made by participants in Cases 1 and 2. Although some participants in Case 3 speak

about the effort of supporting people in complex situations, the emphasis on family support in that case may explain why there are fewer observations about needing more time to support patients in those areas. Where families are available and able to provide support, it is generally seen to reduce the burden on healthcare services. In Case 3, participants instead emphasise resource and capacity issues around caring for patients with little wider social support, particularly those living in rural areas, but this does not have a clear association to social deprivation in that case. Many things can contribute to professionals needing more time to spend with patients in the last year of life, some of which are not to do with social deprivation. While recognising this, complexities that arise at the end of life relating to circumstances associated with social deprivation – poor access to primary care, mistrust, comorbidities, mental health, and substance dependencies, for example – all feasibly contribute to greater time and input from services, particularly when families have difficulties providing informal support to the patient.

The perception that some patients in socially deprived areas need more input and time coincides with observations about having fewer resources and limited capacity to provide that care. While comments about capacity and time are often about the larger system in which participants worked, there is evidence that those working in socially deprived areas have less capacity to support patients in the last year of life. Chris, an urgent care GP in Case 3, summarises some of these pressures in a primary care setting:

I mean General Practice nationally is under a lot of stress at the moment in terms of recruitment. So, you've got fewer GPs looking after larger populations of patients...it's fewer resources and also deprived populations. The way GPs are paid, there's a capitation, that's a bit of an element for deprivation. But if you're looking after a deprived population as a GP it's much harder. It tends to be more chaotic. You've got more people to deal with. You've got drink and drug and mental health problems which are sort of time consuming and complicated. And while all that's going on it just means you've got less time to provide planned good quality end-of-life care for those that you would want to. It's just a resource issue, if you haven't, you haven't got the numbers. If you got a number of docs to see the patients then everybody gets less. (Chris, Referrer GP, Case 3)

While pressures on primary care and other areas of the healthcare sector are a concern for care of all patients, Chris's account highlights the potential for there to be limited capacity to provide care to those

nearing the end of life in socially deprived areas. Not only can some patients in these areas require more time and input because of the nature of their needs, professionals caring for them may have fewer resources and less time to provide support.

Decisions about referring patients to other services often appear partly based on participants' sense of their capacity to provide adequate support to patients in relation to other healthcare providers. Recognising this, some hospice staff and other specialist end-of-life care providers reflect on the appropriateness of such referrals. They wrestle with a desire to maintain good working relationships with other professionals whilst also being concerned about their services filling a gap in the system rather than in patients' needs. Participants who share these experiences are in many instances referring to referrals or relationships in general, rather than those specific to referrers in socially deprived areas. This is especially true for Case 3, where – aside from Chris's experience quoted above – there are very few observations of how capacity issues specific to more socially deprived areas may influence end-of-life care. In contrast, there were several accounts in Cases 1 and 2 of hospice staff reflecting on how referrers in those areas use their services. Hannah, a hospice staff member in Case 1, compares the apparent reluctance of some referrers in the less deprived areas of that case to engage in shared care, to those in the more deprived areas who were seen to refer more partly because of capacity issues:

...they're like that because they really care and they've got the time to do it. Whereas you go to someone at GP1-group where they are dealing with the GP2, the GP3 surgeries, the GP4 surgeries, so where the postcodes are the more demographics we're talking about, they haven't got chance to turn round, so there is a real uneven feel to our referrals into the hospice. (Hannah, Hospice Senior Staff, Case 1)

Becky, who works for the hospice in Case 2, reflects on her role in responding to apparently similar capacity issues in her area:

And this is the thing when you come to the real issues of social deprivation is in these areas there's not enough GPs and the GPs who are there, it's just I don't know how they are carrying on. You know the number of patients they're seeing, the number of things that they're doing.... so I have to go to them sort of saying how can I help you, how can I reduce your workload...

it's hard to get hold of them and when you phone them up they're really busy, it's massive, that's massive...it's not because they're rude, it's because they're swamped. (Becky, Hospice Senior Doctor, Case 2)

There are differences of opinion on whether it was appropriate for the hospice, or other services, to help fill gaps in the wider healthcare sector. In the extract above, Becky embraces the idea of being able to take some of the workload off her GP colleagues. While many participants acknowledge and accept that resource issues can influence referrals, others are more cautious about overstretching their own services. For example, there is concern in Case 2 that the hospice was spreading itself “thinner and thinner” (Val, Hospice Senior Nurse, Case 2) in its efforts to create more inclusive services. Others comment in more general terms, not specifically about social deprivation, about not wanting to fill gaps in the NHS or doing too good a job for fear it would lead to their services being pulled on more. These examples demonstrate that while each hospice is, in some way, committed to increasing access to its services, there is an undercurrent of concern that hospice services are themselves vulnerable to being overburdened. How hospices resolve or address this has consequences for all patients but particularly for those in areas where NHS services are under the biggest strain.

How hospices understand appropriateness in end-of-life care referrals has, sometimes very direct, consequences for how they understand equity in their services. In the extract from her interview above, Hannah describes an “uneven feel” to referrals, perceiving there to be greater numbers of referrals from the region that included the most deprived neighbourhoods of the catchment area, a perception held up when looking at the raw numbers of referrals in that case, where referrals rates were highest in the most deprived 20% of the catchment area (Table 30).

**Table 30. Hospice referrals by deprivation quintile in Case 1**

Deprivation quintile	Referrals (n)	Referral rate <sup>1</sup>
Most deprived - 1	540	14.67
2	395	9.61
3	393	9.36
4	382	9.8
Least deprived - 5	498	11.91
Total	2208	-

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<sup>1</sup>Per 1000 population

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Others in Case 1 also speak about patients in the more rural and less deprived areas of that case potentially being disadvantaged because NHS staff in those areas appear more reluctant to refer. Although recognising the potential for NHS staff to have more time to provide end-of-life care in those areas, one participant describes doing “quite a lot of work” building relationships in the more rural and affluent areas to try to “make it equitable” across the footprint (Claire, Hospice Senior Nurse, Case 1). In contrast, one hospice staff member in Case 2 argues that referrals should be based not just on the needs of patients but also of those close to them and their clinicians. While this was the only time that a participant explicitly includes the needs of referring clinicians in their assessment of appropriate referrals, it is comparable to examples of participants accepting capacity-driven referrals.

Overall, then, there is uncertainty among participants in this study regarding the relationship between needs, appropriate referrals, and equitable services. Given the resource issues in socially deprived areas, how this uncertainty is expressed and resolved has potential consequences for staff attitudes towards referrals from those areas and in how hospices assess socioeconomic inequities in referrals.

#### **7.4.3. Summary of theme**

This theme describes how healthcare professionals negotiate a way forward with patients and other healthcare providers to achieve what they consider to be an appropriate use of services. Participants appear to try to help patients get the best out of services while also recognising the limits to the system and organisations in which they work. Approaches to managing expectations within interactions with patients are shaped by professionals’ perceptions of appropriate use of services, which in turn is driven by how participants understand different providers’ capacity to provide support. Skills, power, knowledge of the system, and time are resources that participants draw on to try and support patients in the last year of life. As hospice staff reflect on the role of themselves and their organisation, and responsibility to the wider healthcare system, they reveal how understanding about appropriateness, need, and capacity can potentially influence access to hospice care in socially deprived areas.

## 7.5. Theme 4: Contradictions between ideal and realistic care

The analysis of participants' accounts so far has explored their perspectives on connecting with patients and their attempts to draw on personal and organisational resources to try to bridge any gaps between patients and services. Some healthcare professionals reflect on a deeper level about what these experiences suggest about their role and the aspirations of the palliative or end-of-life care profession more generally. Even though participants are rarely explicit about the goals of end-of-life care, or how they envisage a good death for a patient, there is a tension running through many accounts between a desire to achieve these goals and the reality of end of life for some patients who are socioeconomically disadvantaged. Although naming those goals for end-of-life care is not the focus of this study, acknowledging and describing the struggle to achieve them draws attention to a contradiction that can arise between professional aspirations and patients' lives. Some of the ways in which health services respond to these contradictions and challenges has been mapped out in the section above. An additional layer to this response concerns the impact this contradiction has on staff and how they rationalise and respond to a tension between idealism and reality in end-of-life care. Some participants respond to this by harnessing the language of patient choice. This section moves away, therefore, from the question of how providers try to connect with and support patients and considers professional expectations and patient-led decision-making within end-of-life care in the context of social deprivation.

Many participants discuss moments when they want to do something for patients but feel they are unable to because of the circumstances of patients' lives. As has already been outlined, the circumstances of patients' lives in socially deprived areas vary considerably both within and across cases. Consequently, the nature of the contradiction between these circumstances and participants' aspirations for patients also varies. Some professionals who discuss these scenarios appear to struggle when they perceive care to fall short or contradict their idea of good end-of-life care. Rachel, a district nurse in Case 2, describes this in the context of wanting to do things "the right way" whilst also respecting a patient:

I mean obviously you go into a classroom and you are taught end-of-life care and out in community it's extremely different, erm, we are taught the right way to do things like you are in a driving test, driving lesson, but you go out there in community and we had a gentleman quite recently who just lived in absolute squalor, erm, and they are, they are the bosses in their

own house really. So, you know, you, so if they've got the capacity, then you know you have to respect that. As much as you would like to scoop them up, put them in a lovely warm hot bubbly bath and comb their hair and cut their nails and everything, you know, you can't always give what you would love to give, you do have to respect the patient. (Rachel, Referrer District Nurse, Case 2)

In describing what she would like to do for a patient, Rachel conveys the intimate and personal nature of her profession. For her, this intimate care is a core component to her role as a district nurse caring for patients nearing the end of life but one she feels she should resist because of another professional tenet, that of respecting the patient. A contradiction between these aspects to her role arises when she feels that respect for a patient's capacity to decide to live a certain way prevents her from fulfilling her desire to provide personal care. Rachel's account is representative of several experiences described by participants where they draw attention to a contradiction between their expectations and what they feel is appropriate for that patient given the circumstances. There is evidence, for example, of hospice nurses becoming upset when patients resist input from healthcare services for reasons described in the first theme, such as mistrust. Similar difficulties arose when a participant's own skillset falls short of what a patient and family require. The difficulties of caring for patients with severe mental health conditions in Case 1, and the lack of psychological expertise staff feel they have, is one example. Here, the expectation of being able to support patients at the end of life is contradicted by patient or family need for high-level psychological care that does not fit neatly into the model of specialist end-of-life care provided in that case. Participants who share these experiences wrestle, with varying amounts of reflection and understanding, with a tension between professional idealism and the reality of some patients' lives and needs in socially deprived areas.

Both hospice staff and referrers taking part in this study sometimes describe conflicting expectations within and across teams about the circumstances in which some patients live at the end of their life and the responsibility healthcare professionals have for those circumstances. Different expectations can lead to different perspectives on whether circumstances contradict end-of-life care goals. In one account, a referrer describes supporting hospice staff to recognise that a patient's seemingly stressful death was "as good as it could have been" (Adi, Referrer Specialist Nurse, Case 2). The referrer suggests that the family of that patient were happy with the circumstances of that death, which had met their expectations, but

the hospice staff had struggled because it did not live up to professional expectations of a death free from physical and emotional pain. In that account, the referrer (Adi) does not feel responsible for achieving a completely pain-free death, only for helping the family to achieve as much as they could; the implication was that the hospice staff do feel responsible for whether the death was pain-free and thus struggle when the circumstances made it difficult to achieve this goal.

While not always explicitly linked to social deprivation, conflicting expectations about end of life goals and responsibility for achieving them are evident in several accounts. It is relevant, for example, to reports of participants trying to persuade colleagues that it is acceptable for patients to die alone or, conversely, that it is not acceptable. Hospice staff can also be in two frames of mind about whether a hospice building is the best place for someone with a serious mental health condition or about tidying up around a patients' home. Threaded through each of these accounts is evidence of differing expectations about the circumstances in which patients should end their life. They also suggest that professionals wrestle with these conflicts and contradictions in interactions with one another; in these accounts, these discussions often seem to occur in response to individual episodes of care. There is little evidence in the interviews of whole teams reflecting more broadly about possible contradictions between their goals and the circumstances of some patients' lives, although that is not to say these discussions do not take place. Any tensions about a conflict between participants' lives in socially deprived areas and professional expectations are, then, part of a larger discussion about appropriateness and acceptability in end-of-life care. While recognising the potential relevance of this discussion to the care of patients across different socioeconomic groups, specific concerns associated with social deprivation – homelessness, severe mental health conditions, substance use, and housing quality – seem in this study to draw out evidence from participants' accounts of conflicting expectations in end-of-life care.

Participants who have spent a greater length of time working with socially disadvantaged populations, particularly in the community, tend to discuss in greater depth about how they respond to some of the circumstances of people's lives discussed above. Comparing experiences across the different cases highlights the potential importance of familiarity with these circumstances in driving how professionals reflect and respond to them. In Cases 1 and 2, where some participants have considerable experience of working in socially deprived areas, several appear to have already reflected on this experience prior to taking part in the research. With some exceptions, it was in these accounts, that participants appear to

respond to tensions in care by shifting their expectations and professional goals in line with the life circumstances of some of their patients in socially deprived areas. In both those cases, the socially deprived areas tend to be clustered together, which perhaps also makes it easier for participants to consider in more general terms the circumstances and behaviours of patients and families in socially deprived areas.

In contrast, participants in Case 3 appear to have fewer experiences to draw on; several comment about the rarity of encountering issues such as homelessness or substance dependency, for example. An exception to this was the account of one urgent care GP who speaks about the widespread alcohol dependencies among patients accessing A&E, many of whom he perceives to be socioeconomically disadvantaged. On the whole, however, a lack of a familiarity with some issues that participants in other cases associate with social deprivation suggests that participants in Case 3 possibly have fewer relevant experiences to reflect on. Some participants in this case suggest a consequence of this was that they were more risk averse when responding to unfamiliar environments. This observation was supported by accounts that suggest a high level of concern about managing, for example, prescription drugs in home environments where there were residents with substances dependencies. The quotes below offer a comparison of one of these accounts in Case 3 to a response to a similar situation in Case 2:

I have a lady who has high alcohol intake who lives in quite dire circumstances...She's quite a vulnerable person because she tends to have different individuals in and out of her flat on a daily basis. So obviously we've highlighted to her that this will affect her end-of-life care because, one, I can't prescribe any opioids to put in that environment...So we are having currently at the moment safeguarding meetings with social services, home housing, financial benefits advisor and now we've raised it with the police as well to look into the background, if we can get information of individuals that are going into her flat. So that's quite a difficult one because worst case scenario is that, one, this lady could end up being deprived of end of life input because she's deemed to have capacity and she's putting herself in that position. (Arlene, Referrer Specialist Nurse, Case 3)

...we certainly had a couple of patients, who were part of an IV drug misuse er, er, gang I suppose. They were dying of lung cancer, they needed pain killers, they had their pain killers,

but you know there was that, how safe is it for us to send that, that patient home which is where they wanted to go but with a whole stock of controlled drugs which their colleagues would like to sell, and we, you know, and so there was that. So, the way we solved that was he had a very limited supply and we monitored it as closely as we could. Sadly, they still did misuse these drugs but it was his choice, he wanted to go back to that. (Kate, Hospice Senior Doctor, Case 2)

Arlene and Kate are both trying to ensure patients had access to medicines but whereas Arlene tries to alter the patient's home environment to meet a pre-defined standard of safety, Kate's account suggests their team had a flexible approach to providing medications that accommodated the patient's home environment. These accounts are representative of broader differences between the cases. With less exposure to some circumstances or behaviours in Case 3, where Arlene worked, there is feasibly less motivation to think about and adapt the goals of end-of-life care; instead healthcare professionals focus on safeguarding staff and medicines in unfamiliar situations. The examples above come from Cases 2 and 3; although participants in Case 1 do not talk explicitly about safety, evidence from that case also suggests that greater familiarity with providing care in socially deprived areas encourages greater reflection about the goals of care. For example, a district nursing team working in the socially deprived areas where many patients have serious underlying mental health conditions and unstable family support are described by one specialist palliative care nurse as resilient and reflective about what can be achieved. Although perspectives vary between and within cases with regards to professional expectations for end of life in the context of social deprivation, all these accounts feed into the broader point being made in this section, that a contradiction can arise between the goals of end-of-life care and the circumstances in which some people live in socially deprived areas. How professionals respond to that contradiction can be understood with reference to their wider experience of caring for patients in socially deprived areas and the nature and intensity of patients' needs in those areas.

Although professionals can vary in their response to contradictions at the end of life, they often adopt a common language when rationalising and justifying their reactions. Participants often try to resolve a tension between goals and reality and to justify their response to this tension using the language of patient choice and patient-led decision-making. The concept of patient choice was used, for example, to rationalise and allow for instances where end-of-life care is not put in, or to justify end of life outcomes

that might be distressing for end-of-life care professionals. This was evident when families resist input from healthcare services, when transient populations fall out of the healthcare system, and when a patient lives in an environment where substance dependencies prevent services from being put in. Sometimes participants explicitly discuss patients making choices or “unwise decisions” (Val, Case 2) that conflict with professional aspirations for end of life but nonetheless are accepted because they are patient-led decisions:

...the socially isolated people, they might have no family at all, but the most difficult thing to deal with about that is the fact that they want to die at home. They are going to die on their own. But, again, that's their choice to do that. I had a man over R2 he did that. He lived in total squalor, you couldn't find anything anywhere. One of the district nurses came with me and it was, she said 'we need to get him out, we need to get him out of here' but actually he wanted to stay there. And he actually died within half an hour of us leaving because she had gone back. And she was distraught and felt that we'd really let him down. But actually, I said he had made that decision that's him but I think we still can't understand why somebody would want to do that. (Val, Hospice Senior Nurse, Case 2)

From Val's perspective, the patient's decision in that instance is acceptable because she saw it as his choice even though it is difficult to understand from the perspective of healthcare professionals. The understanding that a patient had acted with agency and chosen to live a certain life, or to die in a certain way, enables some participants to adopt a position of respect for a patient that also allows them accept deaths that, from a professional perspective, are less than ideal. However, this was not an understanding that everyone involved in end-of-life care in these cases has arrived at. Val describes a district nurse's difficulty in accepting the suggestion that her patient had decided to die alone. Other participants share experiences where the possibility of a patient having an uncomfortable, lonely, or painful death leads to action being taken in a way that contravened a patient's care preferences. This was evident in accounts of wanting to take a patient out of their home and into a setting where their care can be managed safely, such as a nursing home or hospice ward, even when a patient wants to stay at home. Although accounts like Val's tended to be most explicit in their reference to patient choice, these other examples serve to highlight the different ways that patient choice is understood, accepted, and limited by those involved in end-of-life care.

In many of these examples participants perceive patients to be acting with agency. The understanding that patients act with agency is presented as an acceptable justification even in the instances when it is believed to be detrimental to a patient's or family's experiences. Although numerous healthcare professionals in this study adopt this position, there was little reflection about the environment in which patients and families make choices and the assumptions professionals make about autonomy and agency in socially deprived areas. Senior hospice staff member Kate comes close to reflecting on this when referring to choices being genuine:

It is really heart-breaking if, you know, you go into someone's house and literally there is not a carpet on the floor and, you know, their bed is soiled and all the rest of it but if that is actually genuinely their choice then, you know, we have to be careful about what we do about that.

(Kate, Hospice Senior Doctor, Case 2)

In using the word "genuinely" in this statement, Kate signifies the importance of understanding a patient's perspective and their capacity to make autonomous decisions as they near the end of life. Frequently, however, participants do not reflect on their assumptions about a patient's capacity for choices at the end of life and the degree of agency they have over their lives. Harnessing the language of patient choice and patient-led decision-making, no matter a patient's socioeconomic circumstances, encourages respect for patients and families at the end of life but also suggests that participants assume patients have equal agency over their lives. That is not to say that the potential for societal structures to underpin differences in experiences is not recognised; several participants describe what they saw as an unfair distribution of resources within the healthcare sector that could disadvantage those in more deprived areas. These types of structures are sometimes seen as a driving force behind differences in people's experiences and behaviours at the end of life across areas of social deprivation but participants do not reflect in their interviews about the potential consequence this has on a patient's agency over their life and ability to make "genuine" choices.

The arguments suggested in this section draw from what could be considered examples of caring for patients at the extreme end of socioeconomic disadvantage. The observations made about substance dependency or serious mental health conditions are relevant to patients and families experiencing those circumstances but, while associated with social deprivation, are not relevant to everyone living in a

socially deprived area. The challenges and contradictions described above, while relevant, do not reflect the totality of participants' experiences. In Case 3 in particular, where referrals to hospice care were lower in the more socially deprived areas (although not statistically significantly), some participants perceive that access to good family support in that area contributes to seemingly few differences in end-of-life care across areas of social deprivation:

Yeah I can think on the positive side to these people they often have very good family support because these areas are often quite sort of you know they have the traditional family model still ... In terms of what you notice of course is, is the actual place, the house isn't always fantastic you know so but, yeah, I wouldn't say in general terms these people lack support...I wouldn't say, I don't think, I don't see social deprivation has a huge impact on the end-of-life care. (Ian, Referrer GP, Case 3)

No, I've not noticed any specific, the differences you see don't tend to be deprivation related, they tend to be social related.

Interviewer: As in social -

- support. So, it's more I would say the differences you see depend on the individual person and their thoughts and beliefs and the family support they've got around or the friends support they've got around them. Which doesn't necessarily tally with social deprivation. So, I I, I don't think, I don't think, my experience I might be wrong but I wouldn't have said that there is a specific social deprivation issue with palliative services. (Susan, Referrer GP, Case 3)

While participants in Case 3 are conscious of social deprivation being a characteristic of some local areas, the perception of family support for many patients in Case 3 is seen to overcome any potential inequities in care across socially deprived areas. Although the emphasis on the value and availability of family support is strongest in Case 3, where Ian and Susan work, participants in other cases share similar observations. While district nurse Rachel's reflections on the contradictions between some patient's lives and palliative care are used above to support the main argument above, she is also keen to emphasise the positive end of life experiences of patients with good family support:

I remember one little lady who was really, really poor ... and lived in a very poor area in T1 and she had nine children and they were, honestly, that family sat with her day and night and yet I have seen affluent patients who have had nobody and I've learned over the years that it isn't the money, you know, it's the love that is there that carries a patient, that can carry a family through. You know, no matter how poor they are, you know, if they've, the love that was in that family for that lady and they would have done anything for her, they didn't have two penny pieces to rub together, you know, and yet she was beautifully looked after, they didn't need to have carers or anything because they took it in turns as a family... (Rachel, Referrer District Nurse, Case 3)

In drawing attention to love and family presence at the end of life Rachel suggests that a good standard of care – “being beautifully looked after” – is not contradicted by living in economically disadvantaged circumstances. While having family input into care can sometimes create complex situations, the support and involvement of family in patient care is often, as Rachel conveys it, associated with better end of life experiences for patients. Holding this thought together with the earlier reflections on the professional challenges of caring for patients with limited life choices captures a more holistic and nuanced understanding of providing end-of-life care in the context of social deprivation.

Whilst recognising these nuances, the situation described by Rachel in the extract above speaks to similar ideas of autonomy and self-determination explored earlier. In other accounts, participants could move towards accepting difficult situations for professionals by viewing them through the lens of patient-led decision-making. In describing how an economically disadvantaged family cares for their relative without needing “to have carers or anything” Rachel also draws on the positive concepts of autonomy and self-determination when interpreting that situation. Attaching these positive values to situations encountered in socially deprived areas may help participants to accept other aspects of patients’ lives that might seem unfair. However, an unintended consequence of this might be that those who do need “to have carers” are portrayed in a negative light, and their dependency on others seen as less impressive.

### **7.5.1. Summary of theme**

Healthcare professionals interviewed in this study have varying expectations of what can be achieved in end-of-life care in the context of social deprivation and, as such, respond to contradictions between idealistic and realist end-of-life care in different ways. These responses are partly driven by the breadth and depth of their experiences providing care in socially deprived areas and by their understanding of, and attitude towards, patient-led decision-making in that context. The data contributing to this theme suggests that the harnessing of a patient choice narrative to justify some patients' end of life experiences allows healthcare professionals to maintain patient respect but risks assuming patients and families across the socioeconomic spectrum have equal agency over their lives.

## **7.6. Chapter summary**

Drawing on data from interviews with healthcare professionals in three cases, and analyses of referrals to multiple hospice services, this chapter seeks to explore the relationship between socioeconomic position and access to hospice care, with a focus on how factors influence hospice referrals for those living in socially deprived areas. In all three cases, there is little evidence of overall hospice referral rates being associated with social deprivation. However, this chapter presented evidence that the pathways into hospice care and the interactions between patients (and families) and healthcare professionals working in and alongside hospice care are influenced by factors relating to socioeconomic position.

Healthcare professionals perceive their interactions with patients in socially deprived areas to be influenced by phenomena that stretch far beyond death, dying, and end-of-life care. Experiences of supporting patients in the last of year of life in socially deprived areas appear to be underpinned by the characteristics of social deprivation specific to a local area rather than by a general understanding about how people live and die in the context of social deprivation. While responding to the specific characteristics of populations they care for, participants' observations point towards some common themes. They recognise their interactions with patients, and families, are small moments in a much lengthier process of accessing care that patients experience across a lifetime and which involve multiple systems and institutions. When set in the context of social deprivation, this process may involve problematic interactions with services, creating an environment at the end of life that is potentially

imbued with mistrust or conflicting expectations of care. Exploring how participants respond to challenging environments associated with social deprivation in the final section of this chapter reveals a tension in the end-of-life care professions concerning appropriateness, goals of care, and patient choice in the context of socioeconomic disadvantage. While participants acknowledge that the wider socioeconomic and system context can influence interactions with this patient group, there is uncertainty about identifying socioeconomic inequity at the end of life, the ability of end-of-life care professionals to respond to this, and the appropriateness of doing so.

As well as identifying the ways in which a gap can exist between professionals and some patients in socially deprived areas, the findings of this study also concern the points at which professionals and patients interact. They consider how participants draw on different tools to help bridge the gap between patients and services. In both these areas, the interactions between patients and professionals appear intractable from the wider system they are both navigating. The ability of hospices to capture patients, for example, from more socially deprived areas seems somewhat dependent on the organisations' reach into different parts of the healthcare system. Likewise, negotiations with patients and other professionals alike often appear driven by perception of organisational and personal capacity.

The healthcare professionals taking part in this study strive to connect with patients and help them get the best out of end-of-life care services as far as possible. While their experiences are diverse and invite a nuanced understanding of hospice and other end-of-life care in the context of social deprivation, they show how social deprivation can have consequences for the day-to-day provision of this care as well as for professional values and goals. With this, the findings outlined in this chapter call for reflection not only on the practical efforts of healthcare professionals to provide hospice and other end-of-life care to patients in socially deprived areas, but also on the ethical assumptions underpinning attitudes towards best practice in those areas. These topics are discussed in the following chapter, with consideration of how the study's findings compare to the wider evidence base about the practical and ethical challenges of providing equitable access to hospice care.

# Chapter 8. Discussion

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## 8.1. Introduction

The goal of this study was to explore the relationship between socioeconomic position and access to hospice care, specifically looking at whether and how hospice referrals were influenced by factors relating to social deprivation. This involved two specific aims: (1) to explore the association between referrals to hospice care and area social deprivation; and (2) explore the factors influencing how healthcare professionals generate, and respond to, hospice referrals in the context of social deprivation.

While the study set out with a focus on hospice referrals, the inductive approach to the analysis revealed additional insight into the experiences of providing end-of-life care within the context of social deprivation more generally. Going beyond experiences of referrals, the study results and the discussion presented below can also inform broader understanding about equitable end-of-life care and equitable dying.

The primary contribution made by this study is to fill in a knowledge gap about how healthcare professionals understand and respond to the influence of socioeconomic factors on hospice and end-of-life care. As the systematic literature review in Chapter 4 revealed, the existing evidence from the UK tended to focus on socioeconomic factors in relation to patients' use of palliative or end-of-life care, with some additional evidence of patients in disadvantaged positions having greater need for care but fewer informational resources. Additionally, the review pointed towards organisational factors such as resources and time being important drivers of access but there was little evidence explicitly linking this to socioeconomic factors. This study adds to that literature by providing a richer understanding of the role UK healthcare professionals take in negotiating socioeconomically equitable access to hospice and other end-of-life care, the perceived restrictions on the actions they take, and how they experience and resolve tensions between professional aspirations and the reality of dying in the context of social deprivation. By mixing evidence from interviews with hospice referrals data, this study was also able to

link healthcare professionals' experiences with outcomes in a way that has not been done previously to explore the relationship between socioeconomic position and access to hospice care.

The discussion triggered by the study findings moves forward debates about equitable access to hospice care in theoretical and practical ways, a discussion explored in detail in this chapter. Theoretically, it reshapes the candidacy theoretical model of access to suit an end-of-life care context by recognising the active role healthcare professionals have as negotiators both with and for patients during this time in their life. Drawing from outside that theoretical model, the study also centralises the concept of 'recursivity' to understanding equitable access to end-of-life care, recognising that the nature of interactions at the end of life are generated by patients' prior encounters with formal services.

In practical terms, the findings draw attention to how local organisational and population contexts underpin referrals to hospice care in socially deprived areas. Influential organisational contexts may include the degree of integration between hospices and hospitals, and whether community clinical nurse specialist teams fall under the hospice umbrella. As argued in the discussion below, these contexts have consequences for how need and responsibility within end-of-life care are understood in relation to socioeconomic factors. Fundamentally, however, this study suggests that equitable access to hospice care does not begin and end with receipt of a hospice service. Drawing on evidence from outside end-of-life care, the discussion below explores for the first time how ideas about equity and patient choice expressed by participants in this study may, unintentionally, perpetuate inequities in dying. This suggests that ensuring equitable access to hospice care to those living in socially deprived areas requires initiatives that both facilitate referrals and help professionals reflect on how their ongoing interactions and assessments of patients influence equity at the end of life.

### **8.1.1. The structure of this discussion**

The following discussion opens by returning to the beginning of the study, and the original case study propositions that set the direction of the research. These propositions are reconsidered in light of the findings reported in Chapters 6 and 7. The theoretical model of candidacy is also revisited and reflected upon, with consideration given to how this theory may be adapted for future explorations of end-of-life care and socioeconomic disadvantage.

Turning to the empirical evidence, the findings relating to hospice referral rates are compared to literature discussed in previous chapters. Further empirical findings are discussed with reference to two key constructs within the candidacy theory - ‘permeability’ and ‘local operating conditions’ - with consideration of the potential practical consequences for how services are organised and need for care is assessed. Beyond hospice referrals, ideas around ‘good enough’ deaths and patient choice presented in the study findings are considered within a wider policy context, and what this might mean for assessing socioeconomic inequities at the end of life. The discussion ends with a summary of the study’s strengths and limitations, and of the implications for research and for practice.

## 8.2. Propositions

Following case study conventions (Yin, 2018), this study opened by specifying a set of propositions about social deprivation and hospice referrals (see Chapter 4). These propositions reflect the original focus of the study and of the knowledge held at that time about factors that influence referrals across different areas of deprivation. Following the data analysis, they have been re-evaluated and rewritten (Box 1) to incorporate the new knowledge and understanding generated through this study. Revisiting the propositions in this way is typical in case study research and reflects how understanding of the phenomenon of interest evolves and adapts over time (Yin, 2018).

In some ways these propositions are more specific versions of those outlined in the methods chapter. For example, the original proposition 2 suggested that referrals in socially deprived areas are partly driven by how services are organised. This study specified this further by highlighting that services that are able to respond to patients seeking immediate support in moments of crisis, particularly hospital-based settings, may find it easier to pick up patients from socially deprived areas. In other ways, however, these new propositions reflect a shift in the focus of the study and changes to how the relationship between social deprivation and hospice referrals was understood. Whereas originally the propositions were focused around how patient or area characteristics would influence the effect of social deprivation on referrals, the new propositions emphasise professionals' understanding of and response to the local setting in which they worked.

As with any case study underpinned by a critical realist approach, these propositions are not theoretically fixed and instead “provide the basis for developing theory beyond” a case study (Easton, 2010, p.127). Like all knowledge viewed through a critical realist lens, they are fallible and do not reflect a perfect match between theory and evidence (Wyn and Williams, 2012). Nonetheless, they provide some guidance for where future studies of socioeconomic position and hospice care, or end-of-life care generally, in the UK could focus attention. In this chapter, I explore these key findings, and others, in

Box 1: Study propositions	
Study beginning	Study end
<p>(1) Hospice referrals are associated with social deprivation once accounting for the effect of patient, population, and area characteristics.</p> <p>(2) Referrals to hospice services in socially deprived areas are driven both by the way services are delivered and how healthcare professionals and patients interact with one another in those areas.</p>	<p>(1) There is poor evidence that area social deprivation is associated with area hospice referral rates in UK settings.</p> <p>(2) The ease with which patients can be referred to hospice care in moments of crisis, particularly through hospital settings, is likely to facilitate referrals of patients from more deprived areas.</p> <p>(3) Professionals' understanding of and response to needs in more socially deprived areas are underpinned by their experiences of local conditions, including perception of population and organisational context.</p>

context of theoretical and empirical literature on access to healthcare and hospice care, considering the implications they have for practice and the further questions they generate.

### 8.3.Revisiting the ‘candidacy’ model of access

In framing access as a process of establishing a patient’s candidacy for a service, the research drew upon the work of Dixon-Woods et al. (2005, 2006). The candidacy model, introduced in Chapter 3, describes access as a phenomenon generated through a continuous negotiation in multiple interactions between patients and professionals. In these negotiations patients work to establish their candidacy for care and professionals adjudicate it; the interactions and subsequent offers of care are contingent on the local operating conditions in which healthcare is sought and provided. Dixon-Woods et al. (2006) map this process onto seven overlapping stages of candidacy. The implication is that these stages follow a chronological order, although the outcome of an interaction feeds into a new cycle of that process, as visualised in Mackenzie et al. (2013).

Two broad theoretical concepts stood out as pertinent to understanding access to end-of-life care: that access is negotiated; and access as a recursive (or cyclical) process. Exploring the study’s findings using these constructs suggests that the candidacy process does not follow the same chronology in the context of end-of-life care. Instead, it may be that healthcare professionals at the end of life take more of active role in persuading patients of their candidacy. Coming at the end of a patient’s life, the influence of prior experiences of access is arguably at its greatest. The candidacy model can be conceptualised and visualised in a way that emphasises these elements (Fig 7.), with the components of candidacy jointly generating access in a cyclical recursive process, as indicated by the arrows on the enclosing circle.

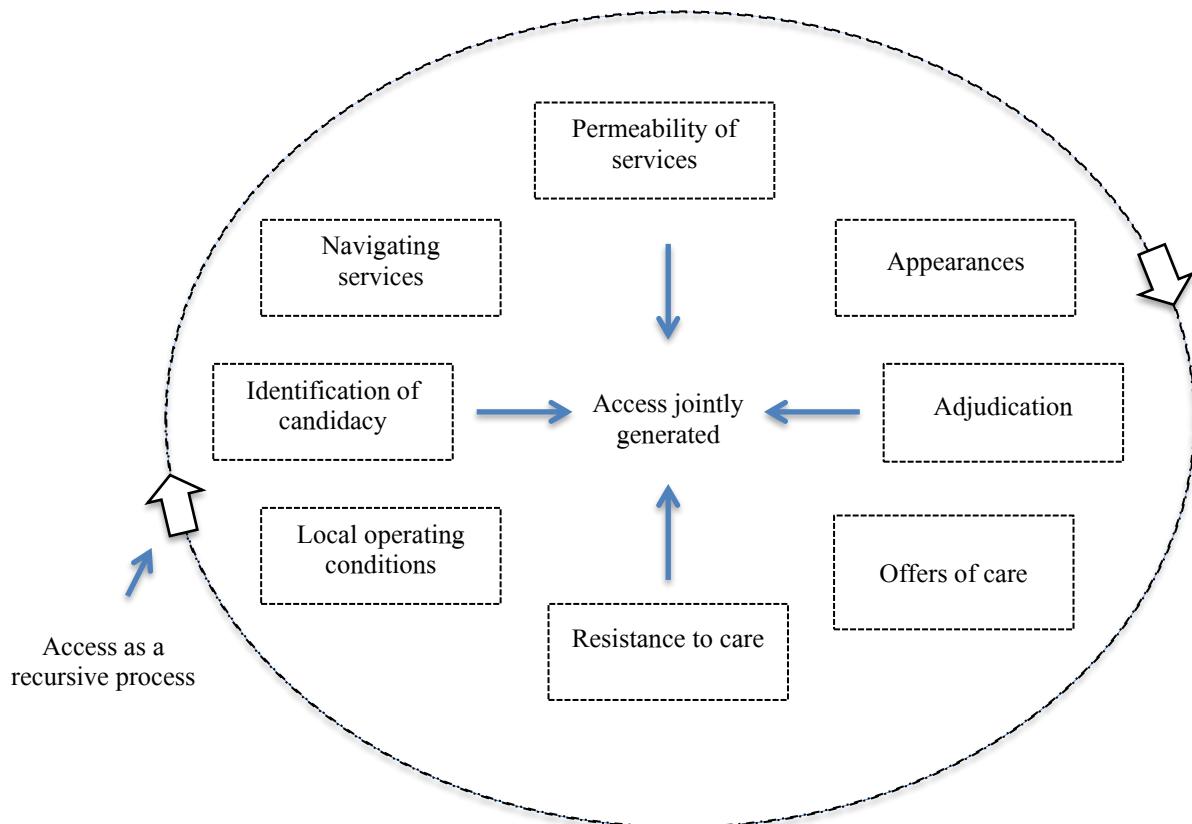


Figure 7: Candidacy model adapted to hospice care

### 8.3.1. Healthcare professionals: the other negotiator

In their observations about making or restricting offers of care, and cautiously trying to bring patients' understanding and expectations in line with their own, participants in this study appeared as negotiators trying to find the best way forward for patients. The suggestion that establishing candidacy for care involves a negotiation between individuals and health services is something emphasised by Dixon-Woods et al. (2006) and reiterated by others. Despite a negotiation inherently involving more than one party, both the original conception of candidacy and subsequent empirical applications of it tend to emphasise the patient as the negotiator, the main agent who is "negotiating legitimacy as a patient" (Llanwarne et al., 2017, Macdonald et al., 2016, Tarrant et al., 2015, Tookey et al., 2018). In contrast, the findings reported in this study draw attention to the negotiating work of a healthcare professional. These findings highlighted how healthcare professionals negotiated both with and for patients (and

families) at the end of life, including negotiating carefully with offers of care to build trust and manage expectations, or acting as advocates for patients struggling to navigate the system elsewhere.

The notion of ‘bridging gaps’ described in this study reflects similar findings from other studies, where vulnerable patients have identified trusted healthcare professionals as important for facilitating continuity in care (Tarrant et al., 2015). Similarly, outreach workers in community healthcare have also been found to be deliberately flexible in the type of care they offer to try and engage patients in preventative care (Mackenzie et al., 2011). Focusing on the role of healthcare professionals in this way highlights both the power inherent to their position but also the personal exchanges that take place in interactions to establish candidacy. Instead of patients negotiating *with* health services, as Dixon-Woods et al. (2006) emphasise, candidacy for care emerges through a negotiation *between* people. This conception, at least in how it was present in this study, reiterates the importance of a concordance between the narratives of professionals and those who could benefit from a service or intervention in order for access to be fulfilled (Kovandžić et al., 2011). The participants in this study were seeking this concordance in their efforts to either raise or lower expectations of patients in socially deprived areas, and in their attempts to gain trust and mutual understanding.

### **8.3.2. Access as a recursive phenomenon**

In addition to ‘negotiation’ being a relevant concept to the experiences of healthcare professionals in this study, the theoretical concept of ‘recursivity’ was also a thread running through many of the findings. Simply, this concept describes how peoples’ experiences and preferences for seeking healthcare are influenced by their prior experiences of seeking and receiving care (Rogers et al., 1999). While Dixon-Woods et al. (2006) do not explicitly mention recursivity in their original work on candidacy, several authors have sought to bring it into their interpretation of how candidacy operates in healthcare environments (Hunter et al., 2013, Kovandžić et al., 2011). Others have conceptualised this as a feedback loop (Andersen, 1995) or represented it as a cyclical process (Mackenzie et al., 2013). In all representations, recursivity is pertinent for understanding access to hospice and other end-of-life care, which will likely occur following multiple encounters between a patient and healthcare professionals, possibly over many years.

Healthcare providers – and researchers - who do not recognise the recursive nature to accessing healthcare are vulnerable to neglecting an important influence on access to end-of-life care for patients experiencing socioeconomic disadvantage, or other social disadvantages. Healthcare professionals in this study spoke about the apparent distrust patients had of healthcare professionals at the end of life following a lifetime of poor encounters with formal services. Reasons for poor encounters were not always detailed but some participants related them to perceived and actual issues with accessing timely healthcare in some areas, particularly the more socially deprived areas. While this study did not capture the patient perspective, this finding mirrors those reported elsewhere of considerable levels of mistrust among socioeconomically and structurally disadvantaged populations at the end of life, with evidence from the UK similar in this instance to that from studies in US and Canadian settings (Lewis et al., 2014, Stajduhar et al., 2019). Failure to recognise that some patient behaviours that may be seen as problematic in end-of-life care – anger, distrust, seemingly chaotic lifestyles – are the consequence of earlier experiences accessing services risks laying the blame at the door of individual patients or families. This tension between a patient’s control over circumstances or behaviours at the end of life and the social determinants influencing those experiences is discussed in greater detail towards the end of this chapter. For the purposes of understanding the theoretical implications, however, suffice to say that potential socioeconomic differences in access to hospice and other end-of-life care are driven by a recursive process of seeking support that begins long before a person becomes seriously ill.

The role of a healthcare professional as a negotiating actor and the relevance of recursivity are highlighted here as two theoretical concepts that run through the study findings. In addition to these overarching concepts, the findings speak to several of the seven components that make up the staged process of candidacy (Dixon-Woods et al., 2006). Without the input of patients or families, it is difficult and inappropriate to use the findings to understand how patients who are socioeconomically disadvantaged may identify their candidacy (stage 1) for hospice care or, navigate services (stage 2) and assert their claim for candidacy (stage 4). Using candidacy as a lens to explore the findings did highlight, however, how offers of hospice care are contingent on local organisational and population contexts. Where some of the findings are more directly comparable to the components of candidacy is, then, in relation to the permeability of services (stage 3) and how local contextual conditions (stage 7) influence interactions between professional and patients at the end of life. To better understand the relevance of

these two stages of candidacy to this research topic, however, it is first useful to revisit and reflect on the findings relating to hospice referral rates and social deprivation.

## 8.4. Discussion of key contributions

### 8.4.1. Hospice referrals: an alternative perspective

The lack of evidence in this study of a statistically significant association between hospice referrals rates and social deprivation corresponds to a similar trend in the UK literature. The narrative review of the literature (Chapter 2) indicated that slightly more studies in the UK had found no evidence of an association between socioeconomic position and receipt of specialist palliative than had found an effect. This study makes a high-quality contribution to that pool of evidence, particularly in triangulating findings from the statistical analyses of referrals with evidence from qualitative interviews. This invites cautious optimism about the ability of hospice services in the UK to receive referrals from across different areas of deprivation, whilst acknowledging that several studies have reported results that would challenge this (Buck et al., 2018, Campbell et al., 2009).

While coherent with the UK literature, this finding contrasts those reported in studies from other countries, calling for reflection about the societal and population contexts in which specialist palliative and end-of-life care is received. In their large review of international evidence, Davies et al. (2019) found that low individual socioeconomic status was associated with reduced odds of using specialist palliative. This finding reflected an overall effect produced by pooling results across different studies, many of which were based in the United States. As the authors allude to themselves, while the overall message is one of inequitable use of specialist palliative care services, the variability in the studies – just over half of which found a null direction of effect – indicates that local contexts are likely important, with the mechanisms by which socioeconomic position influence use of specialist palliative care interacting in complex ways (Davies et al., 2019). While the UK literature and the international literature point to different findings overall, they are united in suggesting that studies can vary considerably in the extent to which they find an association between socioeconomic position and receipt of hospice or other specialist palliative care.

The results of this study further the argument that local context may be key to understanding this variability in study findings. Comparing this study's results to those of a similar piece of research, also conducted in North West England (Campbell et al., 2009), reveal just how 'local' this context can be. Calculating referral rates and using area deprivation as one measure of area socioeconomics, the study conducted by Campbell et al. (2009) is comparable in design to this one. Whereas Campbell et al. (2009) look at referrals to a hospice at home service in a large metropolitan city, this study looked at a breadth of services delivered mostly to towns, coastal, or rural areas. Whereas this study found no evidence of area social deprivation being strongly associated with receipt of hospice care, Campbell et al. (2009) found that referrals fell as area deprivation worsened. Despite being in a similar region of England and using similar methodologies, the studies draw different conclusions. This calls for consideration of the studies' settings, including possible differences in the nature of social deprivation, remit of the hospice services, or – going by the results of this study - the degree of integration with the local hospital. While this level of contextual detail is not published by Campbell et al. (2009), this speaks to the broader point being made: that hospice referrals are perhaps more sensitive to the local context of social deprivation and the organisation of services than to a general phenomenon applicable across all socially deprived areas.

While the statistical results of this study invite cautious optimism about hospice care provision in some socially deprived areas, the analysis of hospice referral rates across different areas only reveals something about the relationship with area socioeconomics, not with socioeconomic position measured at an individual level. Although there are numerous ways to use area measures of socioeconomic position, the analysis of hospice referral rates takes the common approach of investigating the specific relationship area socioeconomics has with a health outcome above any effects at an individual level (Galobardes et al., 2007). A composite measure of area deprivation, such as the one used in this study, is designed to pick up an overall effect of multiple measures and is not sensitive to the heterogeneity in an area or to the specific ways individual measures of socioeconomic position might influence a health outcome. Because it was not clear at the study output what aspect of social deprivation may influence hospice referrals, it was appropriate to use a tool that could capture the joint effect of different indicators. As a similar measure had been used in other studies that found differences in referrals (Buck et al., 2018, Campbell et al., 2009) it was assumed that area deprivation would be able to pick up a socioeconomic

effect on referrals, were it there. A study that prospectively identifies people who are and are not referred would be better suited to measure individual socioeconomic position and thus investigate associations at an individual, not area level. A study of such kind may make a better comparison to those included in the review by Davies et al. (2019), which looked at studies of individual patients' use of services not those reporting area-level patterns.

Although not contesting a global trend of worsening socioeconomic disadvantage being associated with decreasing use of specialist palliative and end-of-life care services, this study calls for reflection about whether and in what circumstances area social deprivation is associated with hospice referrals in the UK. The variability in study findings, within the UK and between countries, suggests that contextual factors such as those described in Chapter 6 and discussed below should be clearly described and included, where possible, in statistical studies of referrals. Questions about the influence of area socioeconomics on hospice referrals call for research that focuses on individual indicators of socioeconomic position, or that includes individual alongside area indicators.

Situating the study findings on hospice referrals data within the wider literature on use of specialist palliative and end-of-life care offered a new perspective on whether patients in socially deprived area are connecting with hospice care. This study was also able to go further, and explore some of the factors influencing referrals. Turning to some of these factors, I draw on the constructs of 'permeability' and 'local operating conditions' in Dixon-Woods et al.'s (2006) candidacy model to try to explain how different contextual conditions may have influenced referrals. Using candidacy as a theoretical springboard, this discussion extends into the practical realm of hospice and end-of-life care and what needs to be considered when assessing and providing equitable care.

#### **8.4.2. The ease of referral: permeability**

While the hospices in this study had not necessarily set out to facilitate referrals from more socially deprived areas, decisions such as integrating into hospital settings or accepting referrals for generalist care created a flexibility that benefitted patients in those areas. Where they were able to facilitate these referrals, the services exhibited what Dixon-Woods et al. (2005; 2006) describe as higher permeability. The authors used the metaphor of a permeable membrane, and its porosity, to describe the ease with

which people can use services (Dixon-Woods et al., 2006). Services with greater permeability are those that require fewer qualifications to use them, such as having few referral criteria, and do not demand the mobilising of many resources or cultural alignment between patients and services. It is the component of the candidacy model that those organising and providing healthcare services arguably have the most influence over, and it features prominently in several studies exploring candidacy in different settings (Hunter et al., 2013, Koehn, 2009, Mackenzie et al., 2011). These studies identified ways in which services can become easier for some patients in more socially deprived areas to access by improving the 'porosity' of services, for example by offering flexible appointment times and different care settings (Mackenzie et al., 2011). In a similar way, when hospices were able to be flexible with why and where patients were referred, this appeared to facilitate referrals of patients from more socially deprived areas.

The finding that service flexibility could facilitate referrals from socially deprived areas may become increasingly relevant as evidence emerges about the effect of the COVID-19 pandemic on the organisation of hospice care in the UK. Early evidence indicates that hospices showed flexibility when adapting their models of care to circumstances triggered by the pandemic, for example by adopting single points of access or changing referral criteria (Dunleavy et al., 2020). It is difficult to know the long-term impact of these changes on patients who are socioeconomically disadvantaged or are, for other reasons, vulnerable from being excluded from hospice care. The more general referrals that might be triggered by having a single point of access may advantage patients who are difficult to identify as nearing the end of life. However, the tightening of referral criteria may reduce the flexibility required to make hospice care relevant to wide range of patients. Research on the long-term impact of services changes following the COVID-19 pandemic may benefit from considering the differential effect changes have on various patient groups, including but limited to patients who are socioeconomically disadvantaged.

The apparent permeability of some services corresponded to patients seeking healthcare at moments of perceived crisis, or following an unexpected change in condition. There is strong and consistent evidence that people in socially deprived areas, or in a more socioeconomically disadvantaged position, are more likely to access emergency services in hospital than socioeconomically advantaged patients, and this pattern extends to the last year of life (Davies et al., 2019, Hanratty et al., 2008a). Dixon-Woods et al. (2006) suggest that is related to a tendency to access care in moments of crisis amongst socially deprived populations. Rather than expecting patients to engage in anticipatory or planned care, more permeable

services are able to respond to these moments and facilitate hospice referrals when it suits patients and families (Mackenzie et al., 2011). This idea of access being jointly facilitated by the permeability of a service and the readiness of a patient is what Pechansky and Thomas (1981) described as the ‘fit’ between a person and a system necessary for achieving access. It recognises that patients in socially deprived areas may be less able or have less time to engage in preventative or anticipatory care and seek emergency care only as a last resort in an otherwise unbearable situation (Mackenzie et al., 2011; Hunter et al., 2013). Extending this argument to end-of-life care, the section below considers in greater detail the relationship between hospitals and hospice referrals in this study. Exploring the finding that patients in socially deprived areas in two cases were more likely to be referred initially by a hospital, this is offered as a counter-example to the dominant narrative of hospitals being associated with negative outcomes at the end of life. Instead, it is argued, they provide an opportunity for improving access to hospice care for people who are socioeconomically disadvantaged by improving the permeability of services.

#### **8.4.3. Reflecting on the role of hospitals**

The finding that hospitals may generate more referrals to hospice services of patients living in socially deprived areas calls for reflection about the role hospital settings have in improving equitable hospice referrals. Hospital settings are generally associated with adverse outcomes at the end of life, with admissions to hospital at the end of life and expected deaths in hospital seen as something to be avoided (Hoare et al., 2019, Robinson et al., 2013). As such, inappropriate hospital admissions and deaths at the end of life have become markers of lower quality in end-of-life care, with many policies and initiatives at a national and regional level pivoted around trying to reduce them (Department of Health, 2012, Taylor et al., 2020). While these efforts may have contributed to decreasing numbers of people dying in hospital in the UK, hospitals were still the place of death for nearly 45% of all deaths in 2019, meaning hospital care is likely to have a considerable influence on many patients’ end-of-life care experiences (Public Health England, 2019).

There is considerable evidence that the role hospital-based care has in people’s end-of-life care increases with worsening socioeconomic disadvantage. Most adverse hospital-related outcomes at the end of life are associated with socioeconomic position, with the likelihood of being admitted to hospital in an emergency in the last year of life and of dying in hospital, for example, greater for those further down

the socioeconomic scale (Barratt et al., 2017, Davies et al., 2019, Walsh and Laudicella, 2017). However, evidence also suggests that patients who are socioeconomically disadvantaged are more likely to perceive a benefit of hospital admission at the end of life than those in more advantaged circumstances, leading to calls for consideration of how structural factors influence expectations and experiences of hospital care (Gott and Robinson, 2018, Robinson et al., 2017). The potential for physical home environments and financial resources to make dying at home difficult, and sometimes undesirable for a patient, also signal why some patients who are socioeconomically disadvantaged may experience benefits from hospital admission at the end of life (Wales et al., 2018). This evidence challenges the dominant discourse that ‘problematises’ hospital in palliative and end-of-life care, responding to calls for a more nuanced understanding of the role of hospitals in care (Robinson et al., 2016).

The findings from this study further the argument that hospitals can be associated with positive outcomes for patients in socioeconomically disadvantaged circumstances. In two cases in this study, patients living in socially deprived areas were more likely to be referred to hospice care via a hospital than by referrers in the community. There were possibly multiple reasons for this, including the tendency for patients to wait until a crisis to seek care, the poor access to primary care in some areas, and the close working relationships between the NHS hospital and hospice staff. The first two - the propensity to wait until a crisis and poorer access to primary care – are characteristics associated with socioeconomically disadvantaged areas that extend beyond end-of-life care to influence numerous health outcomes (Dixon-Woods et al., 2005, Mercer and Watt, 2007). The universality of these issues in disadvantaged areas means it is unlikely they can be overcome by changes within hospice and end-of-life care. This instead calls for hospital to be associated not only with adverse outcomes but also seen as an opportunity for hospices to connect with patients who may be harder to reach in community settings. Strengthening this call, evidence suggests the success of community specialist palliative care at reducing hospital admissions for many patients is less pronounced among patients living in the most socioeconomically disadvantaged areas (Spilsbury et al., 2017). As patients flow around a healthcare system for reasons beyond a hospice’s control, closer working partnerships between hospices and hospitals may offer opportunities to connect with these patients following a crisis or significant change in condition.

The implications of the study findings have so far been discussed largely in their relation to hospice referrals. In offering alternative perspectives to the dominant narratives around hospice referrals and

hospital-related outcomes for patients living in socially deprived, these findings enhance understanding of this topic and invite cautious optimism about the role hospices can have. In other ways, however, participants revealed the constraints and tensions in how they understood and responded to the need for care and support at the end of life in more socially deprived areas. Turning to these findings, the following section continues to explore the conditions in which candidacy is negotiated, moving away from hospice referrals to consider experiences of attending to patients' ongoing end-of-life care needs in these areas.

#### **8.4.4. The conditions of access: local operating conditions**

What several of the findings from this study suggest is that healthcare professionals' observations about what was fair were often driven by their understanding and experience of the local area in which they worked. For example, there was evidence that the amount of experience some professionals had providing care in the context of social deprivation influenced their decisions about patient care. Others understood how historic commissioning decisions could lead to different availability of services for patients in the same area, or how their perception of time and resources set boundaries on their ideas about what could be done for patients. Their assessments about whether and how much input to offer patients were influenced, then, by perceptions of the local context in which they worked. This is what Dixon-Woods et al. (2006) describe as 'local operating conditions', acknowledging the many contextual factors that can set the conditions in which candidacy is negotiated and legitimised.

While recognising that only a small body of literature contributed to the original construction of 'local operating conditions' as a stage of candidacy, Dixon-Woods et al. (2006) suggest that local influences on candidacy are hugely important. Subsequent studies have reiterated this point, although the vagueness of the phrase 'local operating conditions' leads to some uncertainty about what falls under this component. Koehn (2009, p.597) describe the local production of candidacy ranging from "proximity of services to provincial policies". The local (and non-local) organisation of health systems are also relevant; systems that facilitate continuity of care foster more trusting doctor-patient relationships and easier recognition of candidacy (Tarrant et al., 2015, Tookey et al., 2018), as does the perceived time and resource provided to a patient (Methley et al., 2017). Others have demonstrated how policies in healthcare or immigration can influence the dynamic of interactions, and the environments in which they take place (Chase et al., 2017, Llanwarne et al., 2017). This interpretation extends local operating

conditions from the organisation of the immediate services around a patient and professional to a more distal national or potentially international setting. Similarly, in their study exploring domestic abuse disclosure in primary care settings, Mackenzie et al. (2019) critique the candidacy model as failing to explicitly identify how structural factors – including the structural discrimination of different social groups – influence these interactions. Expanding on the original ideas around candidacy being locally produced, the authors draw on a structural competency framework to situate candidacy in a much larger societal context.

The findings from this study indicate that end-of-life care professionals see their assessments of patients as influenced by local conditions, where ‘local’ typically referred to the areas covered by specific healthcare providers, healthcare commissioning groups, or population characteristics associated with specific towns or neighbourhoods. Drawing on some specific findings below, this section of the discussion explores how consideration of these local conditions influences understanding about need and equity, situating these findings within wider literature on assessing need for, and equity in, specialist end-of-life care. The discussion then extends in the final section of this chapter to consider some findings in context of the broader policy environment to end-of-life care and the potential consequences this has for recognising structural influences on equitable dying. ‘Local operating conditions’ are, then, presented in terms of how participants, from both referrer and hospice groups, perceived them – locally - but with calls to recognise the wider societal and policy context that risks perpetuating inequitable dying.

#### **8.4.5. Local conditions for ‘need’**

One of the ways that local conditions influenced healthcare professionals’ assessments of candidacy was in their understanding of what constituted need for hospice care, and how this related to social deprivation. A key question raised by this study’s findings is whether capacity issues in the wider health and social care system are an appropriate reason for referrers to seek and obtain input from hospices or other similar providers of specialist end-of-life care. Some participants saw referrers’ need to offload work as an appropriate reason for seeking hospice input, whereas others opposed this. While this has consequences for all patients, this uncertainty about whether to account for referrer needs is likely to have a disproportionate effect on populations in socioeconomically disadvantaged areas. More likely to experience resource issues, primary care professionals in these areas have less time and capacity to

provide holistic care to patients (Hasegawa et al., 2005). While there is considerable research into defining need for specialist palliative or end-of-life care, few studies have explored the relationship between having fewer resources and less capacity in areas of greater social deprivation and how need for specialist palliative care is classified. Some studies acknowledge that organisational resources, including time and capacity, may increase need for care (Carduff et al., 2018, Tomison and McDowell, 2011). Others suggest that such factors may prevent complex patient needs from being addressed, although this stops short of implying that resource and capacity issues themselves generate need for care (Pask et al., 2018). Uncertainty about whether other services should fill gaps in the wider system creates an ambiguous space into which some patients living in disadvantaged areas may fall, at risk of being variably seen as appropriate or inappropriate candidates for hospice care depending on professionals' attitudes towards local referrer capacity being considered as part of care needs.

Coupled with a potential for there to be less capacity among referrers in more disadvantaged areas, this study found evidence to suggest some patients in these areas may require greater input at the end of life. This corresponds to the widely recognised phenomenon known as the inverse care law, which argues that those with the greatest need typically have access to the fewest resources (Hart, 1971). In relation to their work in end-of-life care, participants often spoke of the additional input involved for caring for patients living in socially deprived areas, including advocating for patients struggling to access other services such as housing or GP appointments, to requiring multiple visits to overcome trust barriers, and arrange multiple onward referrals. This qualitative evidence corroborates data in other studies that suggests areas of greater deprivation generate more visits for specialist palliative care teams (Clark, 1997). It also aligns with evidence of financial concerns and other circumstances causing stress for patients and families who are already socioeconomically disadvantaged, leading to greater need for support at the end of life (Moller, 2010, Payne, 2012). This potential imbalance in the needs of patients calls for greater awareness within the end-of-life care profession between vertical and horizontal equity. Whereas horizontal equity calls for people with the same needs to receive the same treatment, vertical equity recognises that those with different needs will require different levels of input (Chang, 2002). When assessing fairness in distribution of end-of-life care resources, some participants in this study sought equality of referrals across different areas, implying that populations in these areas had equal needs. Hospice staff, and other professionals, who explicitly incorporate the idea of vertical equity into

their assessment of fair resource distribution may be in a better position to assess equity in use of their services.

While this study adds to growing evidence to suggest that some patients and families in socially deprived areas may benefit from greater input from services, the findings suggest that the extent and nature of social deprivation locally is likely to influence the amount or type of input needed. In this study, socially deprived areas where participants perceived a higher prevalence of unmet need for mental health support generated different environments for end-of-life care than those with substantial populations in insecure or multiple occupancy housing, or those with large family networks. This calls for caution when applying findings from other settings to a different area. For example, the suggestion that families in more socioeconomically disadvantaged groups are more likely to have family member close by (Kessler et al, 2005) may be less applicable to areas with high rates of homelessness and multiple occupancy housing; such areas would likely benefit from different types of support for populations at the end of life.

The perception held by some participants in this study, particularly in Cases 2 and 3, that patients in socially deprived areas with family close by had less need for input from formal services at the end-of-life, and in some cases resisted input, also should be interpreted with caution. This may reflect invisible or hidden need rather than low levels of need, with family caregivers of patients at the end-of-life often experiencing high levels of physical and mental burden that may be neglected amid efforts to provide patient care (Kristjanson and Aoun, 2004, Seal et al., 2015). Indeed, in Case 3, participants suggested that referrals to the hospice home nursing service were often triggered by the needs of family caregivers who were becoming exhausted or overwhelmed with caring for their relative. As well as there being the potential for hidden need among some family caregivers in socially deprived areas, it is feasible that this has a gendered pattern to it. While healthcare professionals did not identify, nor were they asked about, the gender of family caregivers, caregiving at the end-of-life is strongly gendered with women often shouldering the burden (Morgan et al., 2016). Therefore, the perceived absence of need in some of the socially deprived areas, particularly in Case 3, may neglect to consider the potential intersection of gender and socioeconomic position that leaves some people doubly disadvantaged when caring for, or being cared by, a loved one (Gott et al., 2020). Research to quantify the extent to which caregiving rests on the shoulders of women experiencing socioeconomic disadvantage, and whether this actually reflects low levels of needs (as some participants in this study assumed) or invisible need, is warranted.

Future research or programmes around inequities at the end of life could also consider how the effects of social deprivation on people's use and ability to benefit from end-of-life care services may relate to a social and historical context specific to a local area. Research into this could draw on the expansive literature on the importance of 'place' in healthcare, a concept that has been used to elucidate complex patterns and differences between areas with similar socioeconomic profiles (Popay et al., 2003). While some studies have explored space and place in hospice care (Moore et al., 2013), few studies have taken this approach to explore the experiences of people who are socioeconomically disadvantaged dying in different spaces, other than the passing comment suggesting that hospice architecture reflects normative middle-class values (Adams, 2016). Others have suggested drawing on a public health approach to fostering more socially equitable end-of-life care (Grindrod, 2020, Reimer-Kirkham et al., 2016, Stajduhar et al., 2020), which could potentially help identify and respond equitably to the local characteristics of socioeconomic disadvantage and their effects on death and dying. Importantly, a localised approach to inequities at the end of life is unlikely to tackle the root causes of those inequities but may be able to mitigate the specific way those inequities influence end of life experiences in a local area.

#### **8.4.6. Responsibility underpinned by organisational context**

In the section above, the discussion explored how local context can shape professionals' understanding of need for palliative care, and the potential consequence of this for those living in more socially deprived areas. In a similar vein, it also appears to shape the sense of responsibility professionals have for attending to patients' different needs. While the philosophy of holistic care underpins hospice care, the study findings and discussion below reveal that in practice the organisational context sets the boundaries to what hospices do and do not do for patients. This has ramifications for the care of patients in socially deprived areas, whose circumstances may call for support beyond what a hospice feels able or comfortable doing.

The foundations of hospice care, and specialist palliative and end-of-life care more generally, lie in the idea that patients should be cared for holistically, with attention given to psychological, social, and spiritual needs, as well as physical symptoms (Randall and Downie, 2006). Following this approach, those involved in this care have a responsibility to attend to the broad causes of a patient's suffering

including those stemming from socioeconomic circumstances (Moller, 2010, Payne, 2012). While orientated around the care of an individual patient, a conception of holistic end-of-life care that encompasses suffering related to socioeconomic circumstances makes the nature of end-of-life care contingent on the societal context in which it is provided. This also makes it hard to discern the boundaries of where professionals should focus their attention. While acknowledging that they should provide holistic care, hospice staff and other end-of-life care professionals in this study spoke about making judgements about where their responsibility begins and ends regarding the social and economic influences on a patient's end of life experiences.

Research with other healthcare professionals suggests there is considerable uncertainty about their responsibility to act upon the socioeconomic determinants of health, and what form that action takes (Gruen et al., 2004). This leaves healthcare professionals to make their own decisions about how to respond to socioeconomic inequities in health, decisions shaped by personal attitudes, experience, workloads and organisational constraints (Exworthy and Morcillo, 2019). In this study, participants recognised that the breadth of support they were able to, and wanted to, offer patients was driven by the scope of the organisation in which they worked. Those working in hospices described how organisational constraints and the model of hospice care set the boundaries on what participants felt they should do. The sense of responsibility varied, then, in relation to the model of hospice care, and between cases. This variability in the model of hospice care is evidenced elsewhere, with the services tending to develop in response to the organisational and healthcare environments in which they work (Cox et al., 2016). Exploring different models in the context of social deprivation, this study highlights the different capacity hospices have for providing broad support to patients living in disadvantaged socioeconomic circumstances. Whether a hospice has ownership of a community clinical nurse specialist team, for example, appears to be important for assessing whether the hospice is best placed to respond to some of the social, psychological, or economic needs associated with social deprivation. This challenges the assumption that all specialist palliative or end-of-life care models include the same offering of holistic care, which is seen as a core component of care and thus not used to differentiate between the type of models in practice (Firth et al, 2019). Instead, the extent of holistic care hospices offer patients in socially deprived areas appears to be driven by the constraints of the organisation rather than by a general philosophy of care.

The finding that capacity determines assessments of need and appropriate care in socially deprived areas can also be considered in light of the impact COVID-19 has had on the hospice sector. There is a concern within the hospice sector that the financial impact of the pandemic may lead to staff redundancies and even hospice closures (Hospice UK, 2020a). As with many healthcare providers, hospices are also vulnerable to temporary staff shortages resulting from exposure to COVID infections. As hospices adjust their services, and model of care, in response to permanent and temporary effects of the pandemic, any reduction in capacity is at risk of disproportionately affecting people in socially deprived areas. This could include, reducing the extent of integrated working with hospitals and other crisis care providers, reduced capacity in clinical nurse specialist teams, or the narrowing of criteria for a hospice referral.

To summarise this section, healthcare professionals' observations and assessments about both what was needed, and what they could and should do for a patient, were bounded by their understanding and experience of the area in which they worked. These findings call for greater certainty about what constitutes need for hospice and other types of palliative or end-of-life care, what equitable use of services might look like in practice, and how this might differ between organisations.

Related to these findings, however, were beliefs about what could and should be achieved for patients dying in difficult socioeconomic circumstances, and their families. As well as being bounded by local conditions, healthcare professionals also sought to understand responsibility and appropriateness by drawing from core professional ideals, particularly that of patient choice. Developing this discussion, the following section considers the professional and policy context that venerates individual autonomy and patient choice as measures of quality in dying, and the consequences this has on how inequities at the end of life are understood and addressed.

#### **8.4.7. Patient choice: a problematic end of life goal?**

The discussion in this chapter has so far focused on situating the findings within the candidacy framework, considering what they reveal about the permeability of hospice care and the influence local operating conditions have on professionals' assessments of patients. Not all the findings outlined in Chapter 6 are best understood using this framework, however. The inductive approach to the analysis provided space for relevant considerations to come to the fore that do not easily fall under the staged

model of candidacy. This includes the tension that participants conveyed between their professional goals and the reality of some patients' lives in socially deprived areas. Some participants attempted to resolve this tension and the less than ideal deaths, from a professional perspective, by drawing on the language of patient choice. While still focusing on the idea of responsibility at the end of life and the context in which care is provided, the following discussion moves away from thinking about the process of accessing care and towards the wider context that underpins responses to how some people die in socially deprived areas.

#### *A 'good enough' death*

The sentiment expressed by some participants in this study that a death was as good as it could have been given the circumstances conveys a broader tension between professional goals and the reality of dying that has been reported in other literature. McNamara (2004) describes how some professionals use the idea of a 'good enough' death to resolve this tension, with a 'good enough' death seen as a satisfactory compromise as long as the principle of patient autonomy has been met. A similar sentiment was present in this study, with some deaths seen as good as they could have been given the options available to a patient and the limits of what healthcare professionals believed they could do. In these instances, supplanting the goal of a 'good death' with a 'good enough death' is positioned as a positive shift that recognises the way people die is contextualised by the way that they lived. Exploring further the idea that a patient who had a troubled life may have a troubled death, Masson (2002) argues that while this can be a negative experience for a patient and their family, it also has a coherence to it that can make sense to family members. Such an experience was present in the account shared by Adi in this study, whereby one patient's emotionally complicated and painful death was seemingly accepted by a family but uncomfortable for hospice staff.

While professionals may encounter good enough deaths across patient populations, its relevance to this study calls attention to how dissonance between professional aspirations and reality manifests in socially deprived areas. While this would benefit from further research examining the extent to which good enough deaths have a socioeconomic pattern to them, the patterns suggested by the qualitative data in this study indicated that circumstances associated with social deprivation could challenge professional goals. While socioeconomic inequities in peoples' lives are themselves morally problematic, responding

to this with the idea of individual autonomy and patient choice, which some participants did, further complicates this. The potential socioeconomic pattern to the dissonance between professional goals and accepting good enough deaths implies there are factors beyond a patient's control influencing their death, challenging the assumption that patients have equal agency over their lives and over their choices at the end of life. This calls for reflection about the ethics of accepting good enough deaths, where patient autonomy and choice is seen as achieved, in areas of greater socioeconomic disadvantage.

#### **8.4.8. Choice, autonomy, and agency**

To understand why participants in this study adopted a patient choice narrative to justify differences in dying, it is necessary to understand the role 'choice' has in end-of-life care more generally. That patients have the right to make choices over how they want to be cared for is a central ethic underpinning healthcare policy in the UK and is a key component to strategies for improving the quality of end-of-life care in recent decades (Greener, 2007, Borgstrom and Walter, 2015). Choice features through the UK's pivotal 2008 End Of Life Care Strategy and in subsequent policy documents, focusing on helping patients to make decisions, primarily about clinical interventions and where they would prefer to die (Henry et al., 2015, Department of Health, 2016, Department of Health, 2008). Choice, therefore, is a desirable outcome in its own right and not just a means to an end.

The emphasis on choice in end-of-life care, and across healthcare, corresponds to a much larger phenomenon of societies being organised around the idea of maximising individual autonomy. Stemming from a popularisation of the idea of 'self' within moral philosophy, an aspiration for individual autonomy became a central characteristic to the dominant liberal thinking in many Western societies, including in bioethics (Woods, 2007, Ho, 2008). With effects of this rippling out into clinical care, the dynamics of clinical interactions shifted to transfer some of the decision-making power from healthcare professionals to patients, challenging the tradition of medical paternalism. Consequently, patient autonomy emerged as a dominant ethic in healthcare (Beauchamp and Childress, 2009), with choice becoming a mechanism by which patients can be empowered to make autonomous decisions including at the end of life (Wilson et al., 2014). While the philosophical and socio-political roots of individual autonomy may feel somewhat distant from the subject of choice in end-of-life care, autonomy is a core value underpinning advanced care planning, a pillar of palliative care that facilitates patients to make decisions about their

future care (Mullick et al., 2013). However, acknowledging the social landscape in which choice (and by extension autonomy) is celebrated opens it up to be critiqued as a reflection of society – and societal aspirations - rather than an objective measure of a ‘good’ death.

Several issues have been raised with the idea of maximising individual autonomy, and using patient choice to do so, in end-of-life care. That patients make decisions with reference to their wider social experience, and not just to maximise benefit to themselves, has led to calls for autonomy to be reconceptualised as ‘relational’ rather than individual (Gómez-Vírseda et al., 2019). These calls often emerge from critical discussions about the limits of individual autonomy and arguments that it neglects the social realities in which people exist and the potential for discrimination of those with different conceptions of autonomy (Gómez-Vírseda et al., 2019). Empirical studies also reveal the different degrees of autonomy and agency people might have and want at the end of life, depending on their personal and social circumstances (Borgstrom and Walter, 2015). Expanding on this, if social realities are relevant to autonomy then this includes the socioeconomic circumstances of people’s lives. When these socioeconomic circumstances have a systematic influence on the quality of some people’s end of life experiences via their capacity for autonomy and subsequent agency then this can be considered an inequity. The amount of power and agency a person has tends to decrease with worsening socioeconomic disadvantage (Dickie et al., 2015) but approaches to care that try to maximise individual autonomy neglect to consider these systematic differences in the capacity of some population groups to act as autonomous agents (Ho et al., 2008). While autonomy and agency continue to be systematically patterned across socioeconomic groups in all areas of life, the choices that people have at the end of life, and their ability to make and act on their decisions, will remain inequitable (Lolich and Lynch, 2017, Grindrod, 2020).

In drawing on a patient choice narrative to justify the difficulties achieving professional goals at the end of the life in socially deprived areas, participants in this study revealed how the principle of individual autonomy can relieve some of the tension between the reality and the ideal in end-of-life care. While facilitating patient choice may bring immediate benefits to some patients, it also places responsibility for that situation on the shoulders of the patient. The study participants who adopted this stance are not alone in doing so. A study of GPs working in some of the most deprived areas of Scotland also found that many intuitively fell back on the idea of patients being individually responsible for changing socially-

determined health outcomes, which the authors suggested reflected a clinical focus on diagnosing and treating individuals (Mackenzie et al., 2020). In a similar vein, seeing personal independent achievement as a positive and desirable attribute may also contribute to why people delivering healthcare programmes often lean towards lifestyle interventions targeting individual behaviours, even when they are aware that health outcomes are socially determined (Mead et al., 2020). However, this focus on individual responsibility can have devastating consequences for those who carry the burden. A study of women in a disadvantaged area of England, found that many embodied this ethic of individual responsibility, fiercely rejecting the idea that their lives may be socially determined and denying themselves any form of dependency to the point of emotional breakdown (Peacock et al., 2014).

In situating the ethical principle of patient choice at the end of life within the wider context of individual autonomy and responsibility, this study reveals the potential for this goal to perpetuate inequities in dying by failing to recognise constraints placed on some patient's agency by socioeconomic forces. While not proffering an answer to how best to manage a fair and equitable balance of responsibility in end-of-life care in the context of social deprivation, the discussion of these findings suggests that professional reflection on what it means to facilitate equitable patient choices is warranted. Rather than rejecting patient choice, hospice staff and others involved in end-of-life care may benefit from considering the systematic structural influences on patient's autonomy and decision-making (Grindrod, 2020). Writing about a public health palliative care project in Australia, Grindrod (2020, pp. 94-95) calls for greater acknowledgement of the "social determinants of choice" to help provide "authentic" choices for those who are structurally vulnerable, drawing upon top-down system change and bottom-up civic participation to effect change. As others have suggested, the ethical framework of social justice may provide the language and tools with which to do this (Reimer-Kirkham et al., 2016). Equally, in its focus on both understanding and acting on structural influences on health and healthcare, structural competency may also offer a way to harmonise individual patient-centred approaches with appreciation of the systematic societal influences on end-of-life care (Metzl and Hansen, 2014, Mackenzie et al., 2019). To some extent, participants in Case 2 drew on structural competency techniques when they sought ways to maintain end-of-life care provision in home environments where residents were drug-dependent. However, the emphasis on patient choice as detached from the structural constraints that drive inequitable choices suggests there is further scope for adopting a structural competency approach in all cases.

## 8.5. Strengths and limitations

This study has a number of strengths and limitations. Broadly, the strengths identified below lie in the overarching methodological approach to the study, which responded to some issues raised in previous research on similar subjects. This included the lack of data linking factors influencing hospice referrals with measurable outcomes, which required a mixed methods approach inclusive of qualitative and quantitative data. An additional strength lies in the novel use of the candidacy model to explore access to hospice care, and in the inductive approach to analysis that helped to generate novel findings relating to how some healthcare professionals draw upon patient choice in the context of social deprivation. However, this research was arguably weakened by approaches taken to measuring key concepts and in the limited perspective of study participants. A discussion of these positive attributes and drawbacks to the research can hopefully help guide the conduct of future studies in this area.

### 8.5.1. Strengths

The study was strengthened by its methodological approach, which drew on multiple methods, adopted innovative approaches, and focused on studying hospice care within a real-life context.

One of the strengths of this approach was that the findings drew both on data about referral numbers and the experiences of those providing end-of-life care. With these different forms of data, both receipt of care and interactions between patients and end-of-life care professionals were explored in the context of social deprivation. This responded to calls to go beyond purely quantitative methods to explore the relationship between socioeconomic position and end-of-life care, using investigative methods that are better suited to understanding how and why different factors may influence access (Walshe et al., 2009, Davies et al., 2019). In practice, finding no statistically significant evidence of differences in the overall number of referrals across areas of social deprivation made it difficult to provide such explanations. However, the sequential mixed methods study design, whereby the quantitative analysis of hospice referrals was followed by qualitative interviews, helped to explore why some specific referral pathways appeared more likely to be taken by hospice patients in more socially deprived areas. The subsequent observations among some participants about hospital-based referrals, for example, helped to explain why patients living in more socially deprived areas may have been referred via that pathway. Few other studies

have used this approach to link hospice referral pathways with a causal explanation related to socioeconomic position.

In using routine data to examine referral rates and pathways into hospice care, the study also benefited from being able to access data on many patients' actual use of services. This included gathering data on referrals to inpatient hospice care, community-based hospice care, and day hospice, as well as range of patient and provider characteristics, which could be linked directly to deprivation at a small area level. In pulling data from hospice records, the study overcame some of the limitations of asking bereaved relatives or carers to accurately report use of services retrospectively, a method employed by some previous studies in this area (Johnson et al., 2017, Dixon et al., 2015, Addington-Hall and Altmann, 2000). As it did not require the collection of new and specific patient data, this method was an efficient way of collecting large amounts of information without considerable input from healthcare professionals. While not the first to use routine data to study end-of-life care and socioeconomic position, this study further highlights the usefulness of this approach for overcoming some of the ethical and practical challenges of recruiting patients and families to palliative and end-of-life care studies (Hanratty et al., 2008a, Davies et al., 2019).

Adopting a multiple case study approach, this research also benefitted from being able to study how different types of hospice care operated in real-life settings. Analysing three cases first individually and then as part of a cross-case comparison, this study drew attention to the importance of local contextual conditions in influencing hospice referrals. This would have been difficult to do if data from different areas were only pooled together into one analysis, as is typical in a mixed methods study that does not use a case study approach (Mason et al., 2015). This study provides further empirical evidence, then, about the appropriateness and usefulness of case study research as a method for studying the complexities inherent to delivery healthcare services, including those within a palliative and end-of-life care setting (Walshe, 2011, Paparini et al., 2020). In focusing first on how the phenomenon of hospice care occurred in each case, the study revealed how understanding of local populations and the local organisation of services drove ideas about equity and appropriateness rather than a general idea of appropriate hospice care. This finding invites reflection on alternative approaches to understanding equitable hospice care that may not have emerged otherwise.

A final methodological strength of the study to emphasise is the use of regional social deprivation ranks, computed from the national Index of Multiple Deprivation (Department of Communities and Local Government, 2015). Relative deprivation is a concept based on the belief that socioeconomic position should be assessed in relation to living standards of everyone else in society at that time (Townsend, 1979). However, it does not necessarily follow that the level of society should be a country (i.e. England) and in this study, deprivation was ranked regionally to capture the extent of inequality within each catchment area. While previous studies have sought to compare the distribution of local deprivation in one city to that in another (Walsh et al., 2010, Baud et al., 2009), the decision to create new ranks from existing national deprivation ranks appears to be a novel approach. This also adheres to the methodology of case study research, where cases are described using data from within a case and not by drawing from data outside the boundaries of that case (Merriam and Tisdell, 2015). While a potential drawback is that the findings from the study may be difficult to compare to other studies in England using national deprivation, the decision to assess deprivation regionally seemed to be further justified in the accounts of interview participants. Apart from a few occasions where healthcare professionals spoke about their experiences in other areas outside the case, most spoke about social deprivation in local terms, comparing local areas and referring to characteristics specific to the area where they worked. This suggests that future studies of relative social deprivation at regional or local levels may benefit from measuring deprivation to reflect local rather than – or in addition to – national inequalities.

The study was also novel in its use of the candidacy model to explore access to hospice care. A consequence of this was that access was presented as something jointly generated by healthcare professionals, patients, and local context, rather than a feature of service availability or a process experienced by patients alone. Seen through this lens, access to end-of-life care could be repositioned as a continuous cycle of experiences rather than a single moment or threshold to be obtained. As well exploring findings through this theoretical lens, the study also included an inductive approach to analysis. This helped to generate novel findings relating to how some healthcare professionals draw upon patient choice in the context of social deprivation. While not necessarily fitting into the candidacy model, this finding highlighted tensions between the idealism and reality of delivering fair and equitable end-of-life care to those experience socioeconomic disadvantage. In drawing on inductive and deductive approaches,

the study's flexible analytical approach was central to generating these findings, and therefore a key strength of this study.

### **8.5.2. Limitations**

In addition to its strengths, this study was also limited in several key areas. The use of area mortality rates as a crude measure of need for palliative care in this study may have failed accurately to capture how need for care is distributed in a population. In using mortality, this study followed the approach taken in other studies, which – while recognising mortality rates do not perfectly capture palliative care needs in a population – considered them to provide a reasonable estimate of the number of people who may benefit from palliative care (Murtagh et al., 2013). While recognising this, not everyone who dies will need a referral to hospice care and mortality fails to capture the holistic needs of a patient population that may reasonably trigger such a referral. Interviews in this study suggest, for example, that pre-existing psychological illness, the nature and extent of family support, and referrer capacity as factors potentially influencing patient 'need' for greater input at the end of life in more socially deprived areas. The findings of this study also indicate that 'need' for palliative care for people dying in the context of social deprivation will vary between localities. It is unlikely that mortality – the number of people dying in an area – will capture these more nuanced and complicated patterns of need across socially deprived areas.

Whilst mortality was acknowledged at the outset of this study as a 'proxy' indicator for the more holistic and complex needs people might have at the end of life, the specific issues this generated for researching palliative and end-of-life care in socially deprived areas only surfaced later on during the data analysis. Indeed, one of the findings from the study concerned the uncertainty about what constitutes appropriate need for palliative care in socially deprived areas. The study limitation arising from the use of mortality rates as a proxy for need mirrors, then, the 'real world' challenges for those assessing need in socially deprived areas. A consequence of this challenge is that, in practice and in research, it is difficult to conclude whether referral area equitable or inequitable. The lack of a more specific measure of palliative care need in populations was a challenge for answering the research question posed by this study, as it was difficult to draw conclusions about equity or inequity in the use of hospice services across socially deprived areas. While population studies continue to use mortality as an estimate, this uncertainty will

persist. Addressing this limitation in both research and practice is, therefore, a priority area for those seeking to address inequities in palliative care.

While the benefits of using routine data have been outlined above, this method of data collection also has weaknesses. Difficulties can arise as a consequence of routine data being collected for purposes other than to answer a specific research question (Davies et al., 2016). In this study, routine data collected by hospices was done so largely for the purposes of clinical record keeping and decision making at the level of individual patients. This potentially contributed to quality issues with the data, when seeking to export and aggregate it for the purposes of analysing overall referrals. For example, for some patients, the referral source was listed as the hospice, although the unique ID for each patient indicated that this was the first time they had been referred to hospice care. Hospice staff were unable to explain why this may have been coded in that way, meaning it is difficult to interpret these data. Additionally, some data that were missing altogether may have been coded in the incorrect place within a patient's record. In these instances, healthcare professionals may have still been able to see information about, for example, diagnosis in the patient's medical record, but this information would not have been included when data were exported. For some missing data, hospice staff involved in the research were able to quickly recode data correctly. However, for other data, this process was too time and resource intensive to be feasible. The study suffered, then, from some data on patient characteristics being missing. While this suggests some results should be interpreted with caution, including the analysis relating to different hospice services in Case 1, there was generally a low amount of missing data and none missing for outcome variables. Consequently, the findings can be stated with confidence for most of the analyses.

A further weakness of this study lies in the decision to focus on end-of-life care in the most socially deprived areas, which prevented exploring potential socioeconomic gradients in end-of-life care. This decision was justified at the outset by the very few studies in UK settings exploring professionals' experiences of providing end-of-life care in the context of social deprivation. While this study has helped to fill this gap in the literature, this approach risks problematising equity in end-of-life care as an issue only for those living and working in the most deprived areas. The strong and consistent evidence of a social gradient to inequities in health (Marmot, 2010, Marmot et al., 2020) and in end-of-life care (Davies et al., 2019) suggests that responses to inequities have to be universal, but with a proportionally greater impact at the bottom of the gradient (Marmot and Bell, 2012). This requires research that considers how

inequity manifests across a gradient and not just among the most disadvantaged populations to influence outcomes at the end of life. In choosing to compare the most deprived areas with all other areas and to largely explore experiences related to the most deprived areas, this study was not designed to pick up how or why inequities in access may follow a gradient in end-of-life care. While acknowledging this, the findings from this study reveal something about providing end-of-life care in socially deprived areas that may help to target universal end of life policies and programmes in a way that has a proportionally greater impact on the most disadvantaged. Such studies can still make a useful contribution to knowledge about how to provide more equitable services.

Finally, the absence of data from the perspective of patients or informal caregivers limits a holistic understanding of the topic. The original intent had been to include the perspective of patients living in the more socially deprived areas and there was considerable effort to recruit patients or family members in the data collection phase of Case 1. Despite effort from hospice staff and myself, very few patients or family members were identified and those patients who were interested in taking part unfortunately died before being able to. Because of these difficulties, the study focus was re-orientated around the experiences of healthcare professionals and no attempts were made to recruit patients in the subsequent cases. The absence of patient perspective means that some factors influencing referrals not obvious to healthcare professionals are likely to have been missed, including for example stigmatising attitudes within healthcare settings (Stajduhar et al., 2019). Rather than presenting a holistic picture of the topic, the findings from this study will complement, and be complemented by, those of forthcoming studies that focus on the experiences of patients and families (Richards, 2019).

### **8.5.3. Reflecting on challenges to patient and family recruitment**

Efforts to recruit patient and family members to this study that would have allowed their views to be explored faced a number of challenges. Such challenges related both to the identification of suitable potential participants and the context in which recruitment efforts took place. This study benefited from having an engaged and enthusiastic clinical nurse specialist working primarily in a socially deprived area who tried to recruit patients, and shared research materials with several patients living in that area who were also enthusiastic about taking part in the study. Therefore, issues of gatekeeping did not appear to be a major barrier to patient recruitment in this study. Instead, the challenge arose partly due to some of

these interested patients fluctuating in and out of ‘crises’, whereby an urgent need would arise often associated with the socioeconomic conditions in which patients were living. This made it difficult to follow up with potential participants and for people to commit to participating. Therefore, an aspect of people’s lives that this study was interested in exploring – living in a socially deprived area – appeared to contribute directly to the difficulties patients had participating in the study.

Efforts were made to recruit participants through channels other than healthcare settings. For example, study adverts were placed in charity shops, cafes, and the local citizens advice bureau in the town centre of one of the most socially deprived neighbourhoods in the study. This resulted in one interested person – the adult child of a parent who had died – getting in touch having seen the advert in the citizen’s advice bureau. However, the parent who had died had lived in an affluent area of a different town and had died many years earlier, before the time period covered by the study, meaning they were not eligible. As this example suggests, using area social deprivation to try to recruit from more disadvantaged population groups may result in uncertainty about potential participants’ socioeconomic positions. This reflects the potential for heterogeneity in individuals’ socioeconomic positions within socially deprived areas, which limits the use of area social deprivation as an identifier of individuals experiencing socioeconomic disadvantage.

The attempts to recruit using study adverts in public spaces also highlighted the importance of setting and context when introducing someone to the research study. During the early stages of this study, recruitment efforts were also explored in a local foodbank; as a volunteer at the foodbank, I realised that some clients were carers or had been carers of friends and family members who had died and thus may be interested in participating in my PhD research. As a volunteer ‘listener’, someone who sits and talks with the foodbank clients before helping them get their food, I was arguably in a good position to build rapport and trust in that setting. In practice, I found that while it was possible to build rapport and discuss the research with people, often those attending the foodbank were not in the best position to engage in the idea of actually participating in a research study. As a volunteer, I was also sensitive to the power imbalance in that interaction, and the emotional strain some people appeared to experience upon coming into the foodbank. Therefore, while there were occasions when it became apparent someone I was speaking to had experiences relevant to the study, it did not feel appropriate at the time to trigger a conversation about study participation.

## 8.6. Implications and recommendations

### 8.6.1. Implications for practice

While this study cannot provide a comprehensive answer to how to provide more equitable hospice services, it has pointed towards some important avenues that hospices and other specialist palliative and end-of-life care providers could explore. A key implication for practice arising from this study is around facilitating hospice referrals of people from socially deprived areas via hospital settings. To encourage referrals of this population group, hospices should explore ways to integrate their services with hospital-based care and adopt a flexible approach to referrals in that setting. This is further bolstered by recent evidence suggesting that greater use of hospital services at the end of life among those experiencing socioeconomic disadvantage is largely due to poor health in that population (Davies et al, 2021). Other studies have also pointed to the positive benefit some disadvantaged populations get from using hospital services (Robinson et al, 2017). While encouraging referrals from community settings is important, it may not overcome some of these reasons why people in disadvantaged areas tend to use hospital care at the end of life. Hospice staff should consider the different role that hospitals play for people experiencing socioeconomic disadvantage at the end of life and work closely with hospital referrals to facilitate referrals of people from more socially deprived areas, particularly if they are struggling to connect with these patients in primary care settings. For one hospice in this study, being physically integrated into a local hospital and adopting a flexible approach to the type of support they provide patients and referrers in hospital settings was particularly helpful in facilitating greater numbers of referrals.

The findings from this study also indicate there is scope for cross-sector learning about how different hospices approach some of the challenges associated with caring for populations experiencing disadvantage. While the three hospices in this study worked in different contexts, and faced somewhat different challenges, there are nonetheless opportunities to learn from one another. Some of the hospices in this study had considerably more experience with, for example, supporting patients in home environments where there were drug dependencies. The approaches to care developed through these experiences remain relevant even for those working in areas where such experiences are rarer. Feeding best practice examples into policy guidance may be an appropriate way to share experiences in a

charitable sector where organisations have to compete for funding and resources, and therefore may be sensitive about discussing the strengths and limitations of their hospice.

Given the analysis of referral rates in this study did not find strong or clear evidence of inequities in referral rates between more and less deprived areas, there is a risk that the results of this analysis may lead to complacency within the hospice sector regarding equitable access to services. A critical implication of this study for hospices, and other palliative and end-of-life care services, is that the delivery of equitable palliative care extends beyond equitable use of services to include the way in which ongoing care and support is provided to patients and families. Hospices organisations should make effort to extend their staff's understanding of equity beyond equitable use of services and as an ongoing feature of the care of people with advanced illness. For example, encouraging staff to reflect on limits of 'patient choice' narratives at the end-of-life for those who are experiencing socioeconomic disadvantage, and how to adapt services around the reality of dying in the context of social deprivation, will help to shift understanding of equity from being about service utilisation, to something that can be achieved in interactions with patients and families. This could be supported by policy guidance being explicit in stating that equity in palliative care does not necessarily mean reaching more people with the same service.

Providing space for discussions within hospice organisation about what it means to provide a socioeconomically equitable service may also help generate a shared understanding of appropriateness and need in the context of social deprivation. Without this, hospice staff may find it difficult to recognise the different ways equity and inequity can foster in their practices. This recommendation stems from the discrepancies found in this study within and between hospice organisations as to what constitutes appropriate (and therefore equitable) referrals in socially deprived areas. Some participants in this study seemed troubled by circumstances they encountered when supporting people in the context of social deprivation, others had resolved it in their own way, and others appeared not to have thought much about it. This calls for professionals to have a space in which they can reflect and share perspectives about what they can and should do to help patients who arrive at their door having experienced a lifetime of socioeconomic disadvantage. Such discussions could centre around what equity means to different people involved in the care of someone with advanced illness, the role of hospices in responding to complexity related to socioeconomic conditions, and whether need for care includes referrer needs,

recognising the potential for this to lead to unequal numbers of referrals and providing different types of support across different areas.

### **8.6.2. Recommendations for future research**

Some implications for future research have been scattered throughout this chapter but key considerations will be reiterated here. From a methodological point of view, this study highlighted the potential limitation of using mortality as a crude measure of population level palliative care need. Developing a composite measure of population need that can incorporate the holistic ideals of palliative care, and gaps in the wider health and social care system, would strengthen population studies of referrals to hospice care and other specialist palliative or end-of-life care providers. Some initial work has been done in this area but could be expanded and examined in different settings (Schuurman et al., 2018).

Improved methods of estimating population needs would depend on better understanding of what ‘need’ for palliative care means and looks like to different groups of people at the receiving end of palliative care. For example, there is poor evidence, particularly within the UK, on what people living and dying in the context of social deprivation understand their needs to be at the end of life. Evidence from this study suggests that need for palliative and end-of-life care in socially deprived areas can sometimes be perceived as more complex by healthcare professionals. However, the presence of families in some socially deprived areas was also sometimes interpreted by participants as an indication of less need. Listening to the views of people with advanced illnesses, and their families, who have experience of socioeconomic disadvantage is critical to understanding whether the perceptions of service providers reflect those who could benefit from support. Incorporating this evidence into a composite measure of population need, such as that described above, is critical to ensure that need for palliative care can be measured accurately.

When exploring the experiences of people with advanced illnesses researchers may benefit from drawing more explicitly on intersectionality as a lens through which to examine those experiences. As described in the background of this thesis, intersectionality is a term that describes how experiences of (dis)empowerment and (dis)advantage relate to an individual’s multiple identities (e.g. socioeconomic position, gender, and race). When studying potential inequities in palliative care there is value about

thinking how these identities may interact to influence people's end-of-life experiences. The findings from this study, which focused on areas of mainly coastal deprivation in North West England, point to two particular areas for further research. The first concerns the interaction of identities and narratives attached to a particular place and the socioeconomics of that area. Future research could explore how the identity of a place where someone lives (e.g. 'up and coming', 'holiday town', 'left behind neighbourhood') interacts with their individual or community socioeconomic position to influence expectations of the end of life, and of dying. Secondly, some evidence from the third case in this study, hinted at the potential for there to be unmet need that was disproportionately affecting female family caregivers in socially deprived areas, who were arguably at greater risk of exhaustion. There was insufficient data in this study to explore this in any depth. Future studies could explore the burden of caregiving in the context of socially deprived areas, the potential for this to be gendered, and the link this may have with family exhaustion and hospital admissions at the end of life of people living in the most socially deprived areas. Such evidence could be used to target interventions for this particular group, were they found to have unmet need for support.

Future research could also explore the most effective models of working with hospital-based staff that facilitates referrals of patients from more socially deprived areas. This study provides further evidence on the potential positive outcomes that can arise from using hospital services at the end of life by people living in socially deprived areas. However, better understanding of how to integrate hospice and other specialist palliative care services into hospital settings in a way that effectively supports people experiencing socioeconomic disadvantage is required. Such evidence may be particularly helpful for hospices and other specialist palliative care services that are struggling to reach people living in more socially deprived areas through community-based referrers.

The suggestion that end-of-life care professionals try to resolve a tension in their work in socially deprived areas, and did so by drawing on patient choice narratives, opens up questions about the consequence this has for social inequities in dying. It is unclear, for example, how patients and families with experience of socioeconomic disadvantage feel about their ability to make and realise choices at the end of life. In building on earlier critiques of choice as a potentially problematic measure of quality in end-of-life care, and related ideas around autonomy, this study also suggests that research into alternative approaches to measuring equitable outcomes at the end of life is warranted. Outcomes that can both

reveal the differences in how people die – beyond where they die and the services they can use - may also focus attention on some of the more fundamental causes of those differences. Qualitative research methods could be used to identify the outcomes important to different population groups, including those experiencing socioeconomic disadvantage.

The candidacy model of accessing hospice care proved to be a useful framework for exploring some of ways in which healthcare professionals negotiated access to end-of-life care with patients and families in the context of social deprivation. There are several ways this model of care could be developed in the field of palliative and end-of-life care. For instance, healthcare professionals spoke about patients and families' mistrust of services, and their prior encounters with formal services across a lifetime, influencing their interactions with professionals at the end of life. It would be interesting to explore from the perspective of patients and families whether they shared this interpretation and whether mistrust was indeed a factor influencing their 'identification of candidacy' and 'navigation of services', to draw on concepts defined within the candidacy model. When used to explore socioeconomic (and other) inequities in access to palliative and end-of-life care, the candidacy model would benefit from greater integration of socio-structural factors that can influence equitable access. In other palliative and end-of-life care research, the principles of public health, social justice, and social determinants of dying have been posited as useful conceptual tools for those seeking to tackle social inequities at the end of life (Giesbrecht et al, Grindrod et al, 2019). Future studies could look at integrating these principles with the candidacy model with the aim of generating an overarching model that acknowledges the lengthy and distinct histories of 'access to healthcare' and 'social determinants' theory.

#### *Advancing research methodologies*

This study demonstrated the value of mixing qualitative and quantitative methods in a case study approach when exploring socioeconomic inequities in palliative and end-of-life care. However, there is considerable scope to further develop the use of quantitative methodologies within case study research, and in this subject area. Future research could explore ways of using statistical methods as part of the comparative analysis conducted during the cross-case component of a multiple case study analysis. A random effects analysis where each case is included as a random effect – or other statistical approaches to comparing groups or levels in data – would be an innovative development in quantitative or mixed

method multiple case study research. Such an approach may provide greater clarity over how to systematically and rigorously compare multiple cases. However, stemming from a worldview that is inherently more positivist, any use of statistical methods in this way should be accompanied by a discussion of the philosophical underpinnings of such an approach, and how that might conflict or complement the existing case study approaches described by Yin (2018) and other methodologists.

Further to advancing statistical cross-case analytical approaches, more advanced statistical methods could be used to answer the 'how' questions commonly addressed by case studies. It is possible to address such questions from a predominantly qualitative perspective, the approach largely taken in this study. An alternative might be to use mediational statistical modelling techniques, such as structural equation modelling, which could allow for exploration of the factors that mediate the effect of social deprivation on access to hospice care. For research addressing issues around equity in palliative care, there is also scope for using statistical models to explore questions about which groups are more or less likely to experience inequities in access and other palliative care outcomes. This study highlighted, for example, the heterogeneity of people's lives in areas of social deprivation and the different population groups that can live in those areas (e.g. those with families, socially isolated, older populations, geographically isolated, people with mental health conditions). Using moderation analyses to explore 'for whom' access to hospice care is equitable or inequitable would provide useful insight for those seeking to mitigate inequities.

Reflecting on some of the challenges faced when attempting to recruit patients and families living in socially deprived areas in this study, there are some lessons that can be applied to future studies exploring end of life experiences in the context of socioeconomic disadvantaged. Future research into the relationship between socioeconomic disadvantage and patients' and families' perspectives on access to care and choices at the end of life would benefit from adopting flexible approaches that can accommodate sudden changes in a person's situation related to socioeconomic circumstances. Such an approach is likely to benefit from building longer term and trusting relationships, particularly given the prominence of mistrust in interactions between patients and healthcare professionals documented in this study. Indeed, the interest in the study that some patients expressed to the clinical nurse specialist supporting recruitment was likely the result of the nurse having put in considerable effort over a longer period to build up trust with that person and their family. Finding individuals in other settings (e.g. Citizens Advice

organisations and other non-clinical support services) who have pre-existing relationships with potential participants and are engaged in the research is also likely to be beneficial. Additionally, other ways of measuring socioeconomic position in addition or instead of the social deprivation of the area where people live are recommended. A subjective measure of socioeconomic position could be used at the recruitment stage, for example the MacArthur Scale of Subjective Social Status (Adler et al. 2000).

## 8.7. Summary

Situating the findings within a body of literature related to hospice referrals, access to healthcare, and autonomy at the end of life, this chapter has presented the study's contributions to discussions around equitable hospice and other end-of-life care. These contributions include challenging the dominant narratives around inequitable hospice referrals and the role of hospitals in end-of-life care, but also demonstrating the contribution that local context has in how professionals understand and respond to the needs of patients in socially deprived areas. As well as addressing the original question about how factors influence hospice referrals in more socially deprived areas, the inductive approach also led to additional insight into how approaches to patient care may be unintentionally perpetuating inequities by drawing on patient choice narratives. It also led to adapting the candidacy model of access to hospice care, acknowledging the active role healthcare professionals have as negotiators both with and for patients, as well as the recursive pattern to access that influences experiences tied to socioeconomic factors. Overall, the study points towards a number of further questions and considerations relevant for those interested in researching and working to reduce socioeconomic inequities in access to hospice care.

## Chapter 9. Conclusion

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A fundamental concern underpinning this study was that the access people have to healthcare at the end of life is unfairly determined by the socioeconomic circumstances of their lives. Exploring this concern, this study aimed to improve understanding about the relationship between socioeconomic position and access to hospice care, focusing on hospice referrals. While finding little evidence that hospice referral rates are associated with social deprivation, the findings pointed towards a number of factors that may influence on-going access to care at the end of life for those living in the most socially deprived areas. It provides further evidence about the action healthcare providers could take to understand and address issues related to inequitable access to hospice care for people in a more socioeconomically disadvantaged position.

In shifting attention from the question of who receives services to how healthcare professionals interact with patients at the end of life, this study encourages movement away from an understanding of equity at the end of life pivoted around use of services. This study suggests that equitable access to hospice and other end-of-life care plays out within interactions between healthcare professionals and patients. The suggestion that local population and organisational context underpin participants' ideas about appropriateness and responsibility also points towards fairness in end-of-life care being locally derived rather than a universally understood phenomenon. This has ethical and practical consequences for how equity and fairness are understood and measured, something that could benefit from being considered in greater depth if equity is to remain a fundamental ambition for hospice care.

I hope this thesis is cause for cautious optimism about who receives a hospice referral, and how services can be organised in such ways to facilitate referrals of patients from the most socially deprived areas. Equally, the study reiterates a warning to remember that equitable access to hospice care does not begin and end with a referral. The factors influencing equitable access to hospice and other end-of-life care begin long before a person needs that care, and continue in interactions between patients and professionals after someone has connected with a service. Understanding how equitable access is generated within these on-going interactions will facilitate fairer access to hospice care in the future for people living in socially deprived areas.

## References

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ADAMS, A. 2016. Home and/or hospital: The architectures of end-of-life care. *Change over Time*, 6, 248-263.

ADAY, L. A. & ANDERSEN, R. 1974. A framework for the study of access to medical care. *Health services research*, 9, 208-220.

ADDINGTON-HALL, J. & ALTMANN, D. 2000. Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? *Journal of Advanced Nursing*, 32, 799-806.

ADDINGTON-HALL, J., ALTMANN, D. & MCCARTHY, M. 1998. Which terminally ill cancer patients receive hospice in-patient care? *Social Science & Medicine*, 46, 1011-1016.

ADLER, N. E., EPEL, E. S., CASTELLAZO, G., & ICKOVICS, J. R. 2000. Relationship of subjective and objective social status with psychological and physiological functioning: Preliminary data in healthy, White women. *Health Psychology*, 19(6), 586-592.

ADLER, N. E. & REHKOPF, D. H. 2008. U.S. Disparities in Health: Descriptions, Causes, and Mechanisms. *Annual Review of Public Health*, 29, 235-252.

AGARWAL, S., JAKES, S., ESSEX, S., PAGE, S. J. & MOWFORTH, M. 2018. Disadvantage in English seaside resorts: A typology of deprived neighbourhoods. *Tourism Management*, 69, 440-459.

AHMED, N., BESTALL, J. E., AHMEDZAI, S. H., PAYNE, S. A., CLARK, D. & NOBLE, B. 2004. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine*, 18, 525-542.

ALDRIDGE, M. D., HASSELAAR, J., GARRALDA, E., VAN DER EERDEN, M., STEVENSON, D., MCKENDRICK, K., CENTENO, C. & MEIER, D. E. 2015. Education, implementation, and policy barriers to greater integration of palliative care: A literature review. *Palliative Medicine*, 30, 224-239.

ALLSOP, M. J., ZIEGLER, L. E., MULVEY, M. R., RUSSELL, S., TAYLOR, R. & BENNETT, M. I. 2018. Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliative Medicine*, 32 1322-1333.

ANDERSEN, R. M. 1995. Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behavior*, 36, 1-10.

ANDREWS, N. & SEYMOUR, J. 2011. Factors influencing the referral of non-cancer patients to community specialist palliative care nurses. *International Journal for Palliative Nursing*, 17, 35-41.

BABITSCH, B., GOHL, D. & VON LENGERKE, T. 2012. Re-revisiting Andersen's Behavioral Model of Health Services Use: a systematic review of studies from 1998-2011. *Psycho-social medicine*, 9, Doc11.

BAKER, C. 2019. Health inequalities: Income deprivation and north/south divides. . *Insight Diseases*. London: House of Commons Library.

BARCLAY, S., WYATT, P., SHORE, S., FINLAY, I., GRANDE, G. & TODD, C. 2003. Caring for the dying: how well prepared are general practitioners? A questionnaire study in Wales. *Palliative Medicine*, 17, 27-39.

BARRATT, H., ASARIA, M., SHERINGHAM, J., STONE, P., RAINES, R. & COOKSON, R. 2017. Dying in hospital: Socioeconomic inequality trends in England. *Journal of Health Services Research & Policy*, 22, 149-154.

BAUD, I. S. A., PFEFFER, K., SRIDHARAN, N. & NAINAN, N. 2009. Matching deprivation mapping to urban governance in three Indian mega-cities. *Habitat International*, 33, 365-377.

BEATTY, C. & FOTHERGILL, S. 2003. The Seaside Economy: The final report of the seaside towns research project THE SEASIDE ECONOMY The final report of the seaside towns research project. *The Seaside Towns Research Project*. Sheffield: Centre for Regional Economic and Social Research.

BEAUCHAMP, T. & CHILDRESS, J. 2009. *Principles of biomedical ethics*, Oxford, Oxford University Press.

BECCARO, M., COSTANTINI, M., MERLO, D. F. & THE, I. S. G. 2007. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *BMC Public Health*, 7, 66.

BEERNAERT, K., DELIENS, L., PARDON, K., VAN DEN BLOCK, L., DEVROEY, D., CHAMBAERE, K. & COHEN, J. 2015. What Are Physicians' Reasons for Not Referring People with Life-Limiting Illnesses to Specialist Palliative Care Services? A Nationwide Survey. *PLoS one*, 10, e0137251-e0137251.

BÉLANGER, E., RODRÍGUEZ, C. & GROLEAU, D. 2011. Shared decision-making in palliative care: A systematic mixed studies review using narrative synthesis. *Palliative Medicine*, 25, 242-261.

BHASKAR, R. 1975. *A realist theory of science*, London, Routledge.

BICKERDIKE, L., BOOTH, A., WILSON, P. M., FARLEY, K. & WRIGHT, K. 2017. Social prescribing: less rhetoric and more reality. A systematic review of the evidence. *BMJ Open*, 7, e013384.

BLACKWELL, D. L., MARTINEZ, M. E., GENTLEMAN, J. F., SANMARTIN, C. & BERTHELOT, J.-M. 2009. Socioeconomic Status and Utilization of Health Care Services in Canada and the United States: Findings From a Binational Health Survey. *Medical Care*, 47, 1136-1146.

BORGSTROM, E. & WALTER, T. 2015. Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Social Science & Medicine*, 136-137, 99-105.

BOSSUYT, N., VAN DEN BLOCK, L., COHEN, J., MEEUSSEN, K., BILSEN, J., ECHTELD, M., DELIENS, L. & VAN CASTEREN, V. 2011. Is Individual Educational Level Related to End-of-Life Care Use? Results from a Nationwide Retrospective Cohort Study in Belgium. *Journal of Palliative Medicine*, 14, 1135-1141.

BOWLES, K. H., FOUST, J. B. & NAYLOR, M. D. 2003. Hospital discharge referral decision making: A multidisciplinary perspective. *Applied Nursing Research*, 16, 134-143.

BOYATZIS, R. E. 1998. *Transforming qualitative information : thematic analysis and code development*, Thousand Oaks, Sage Publications.

BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101.

BRAUN, V. & CLARKE, V. 2012. Thematic analysis. In: COOPER, H., CAMIC, P. M., LONG, D. L., PANTER, A. T., RINDSKOPF, D. & SHER, K. J. (eds.) *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological*: American Psychological Association.

BRAUN, V. & CLARKE, V. 2019. Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health*, 11, 589-597.

BRAUN, V., CLARKE, V. & WEATE, P. 2016. Using thematic analysis in sport and exercise research. In: SMITH, B. & SPARKES, A. C. (eds.) *Routledge handbook of qualitative research in sport and exercise*. London: Routledge.

BROGAN, P., HASSON, F. & MCILFATRICK, S. 2019. Lessons learnt: examining the use of case study methodology for nursing research in the context of palliative care. *Journal of Research in Nursing*, 24, 446-459.

BROOM, A., KIRBY, E., GOOD, P., WOOTTON, J. & ADAMS, J. 2013. The art of letting go: Referral to palliative care and its discontents. *Social Science & Medicine*, 78, 9-16.

BUCK, J., WEBB, L., MOTH, L., MORGAN, L. & BARCLAY, S. 2018. Persistent inequalities in Hospice at Home provision. *BMJ Supportive & Palliative Care*, 10, e23.

BUNNISS, S. & KELLY, D. 2010. Research paradigms in medical education research. *Medical Education*, 44, 358-366.

BURT, J. 2011. Back to basics: researching equity in palliative care. *Palliative Medicine*, 26, 5-6.

BURT, J., PLANT, H., OMAR, R. & RAINES, R. 2010. Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. *Palliative Medicine*, 24, 641-650.

BURT, J. & RAINES, R. 2006. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. *Age and Ageing*, 35, 469-476.

CALNAN, M. & ROWE, R. 2006. Research trust relations in health care: conceptual and methodological challenges - introduction. *Journal of Health Organisation and Management*, 20, 349-58.

CAMERON, A. C. & TRIVEDI, P. K. 1998. *Regression Analysis of Count Data*, Cambridge, Cambridge University Press.

CAMPBELL, M., GRANDE, G., WILSON, C., CARESS, A.-L. & ROBERTS, D. 2009. Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK. *Palliative Medicine*, 24, 403-409.

CANDY, B., HOLMAN, A., LEURENT, B., DAVIS, S. & JONES, L. 2011. Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence. *International Journal of Nursing Studies*, 48, 121-133.

CARDUFF, E., JOHNSTON, S., WINSTANLEY, C., MORRISH, J., MURRAY, S. A., SPILLER, J. & FINUCANE, A. 2018. What does 'complex' mean in palliative care? Triangulating qualitative findings from 3 settings. *BMC Palliative Care*, 17, 12.

CARE QUALITY COMMISSION 2016. Addressing inequalities in end of life care Overview report. Newcastle Upon Tyne: Care Quality Commission (CQC).

CARSTAIRS, V. 1995. Deprivation indices: their interpretation and use in relation to health. *Journal of Epidemiology and Community Health*, 49, 3-8.

CARTWRIGHT, A. 1992. Social class differences in health and care in the year before death. *Journal of Epidemiology and Community Health*, 46, 54-57.

CHANG, W. C. 2002. The meaning and goals of equity in health. *Journal of Epidemiology and Community Health*, 56, 488.

CHASE, L. E., CLEVELAND, J., BEATSON, J. & ROUSSEAU, C. 2017. The gap between entitlement and access to healthcare: An analysis of "candidacy" in the help-seeking trajectories of asylum seekers in Montreal. *Social Science & Medicine*, 182, 52-59.

CHEW-GRAHAM, C., SLADE, M., MONTANA, C., STEWART, M. & GASK, L. 2007. A qualitative study of referral to community mental health teams in the UK: Exploring the rhetoric and the reality. *BMC Health Services Research*, 7, 117.

CLARK, C. R. 1997. Social deprivation increases workload in palliative care of terminally ill patients. *BMJ (Clinical research ed.)*, 314, 1202-1202.

CLARK, D. 2007. From margins to centre: a review of the history of palliative care in cancer. *The Lancet Oncology*, 8, 430-438.

CLARK, D. 2014. Two reports that shaped the history of end of life care in the United Kingdom. Available from: <http://endoflifestudies.academicblogs.co.uk/author/davidclark/page/11/> [07 November 2019].

CLARK, D., SMALL, N., WRIGHT, M., WINSLOW, M. & HUGHES, N. 2005. *A Bit of Heaven for the Few? An Oral History of the Hospice Movement in the United Kingdom.*, Lancaster, England, Observatory Publications.

CLAYTON, J. M., BUTOW, P. N. & TATTERSALL, M. H. N. 2005. When and How to Initiate Discussion About Prognosis and End-of-Life Issues with Terminally Ill Patients. *Journal of Pain and Symptom Management*, 30, 132-144.

COCHRANE PAIN, PALLIATIVE, AND SUPPORTIVE CARE. 2017. *Searching for studies* [Online]. Cochrane Pain, Palliative, and Supportive Care. Available: <https://papas.cochrane.org/resources/searching-studies> [Accessed 19 February 2018].

COLLINS, A., MCLACHLAN, S.-A. & PHILIP, J. 2017. Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers. *Palliative Medicine*, 31, 825-832.

COMMINS, P. 2004. Poverty and Social Exclusion in Rural Areas: Characteristics, Processes and Research Issues. *Sociologia Ruralis*, 44, 60-75.

COX, S., MURTAGH, F. E. M., TOOKMAN, A., GAGE, A., SYKES, N., MCGINN, M., KATHORIA, M., WILDERSPIN, H. & CHART, L. 2016. A review of specialist palliative care provision and access across London - mapping the capital. *London journal of primary care*, 9, 33-37.

CRENSHAW, K. 1991. Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, 43, 1241-1299.

CRESWELL, J. W. 2009. *Research design : qualitative, quantitative, and mixed methods approaches*, Los Angeles, Sage Publications.

CROTTY, M. J. 1998. *The Foundations of Social Research: Meaning and Perspective in the Research Process*, London: SAGE Publications.

CROWE, S., CRESSWELL, K., ROBERTSON, A., HUBY, G., AVERY, A. & SHEIKH, A. 2011. The case study approach. *BMC Medical Research Methodology*, 11, 100.

D'AMBRUOSO, L., BYASS, P. & QOMARIYAH, S. N. 2010. 'Maybe it was her fate and maybe she ran out of blood'. Final caregivers' perspectives on access to obstetric emergencies in rural Indonesia. *Journal of Biosocial Science*, 42, 213-241.

DAHLGREN, G. & WHITEHEAD, M. 1991. Policies and strategies to promote social equity in health. Stockholm: Institute for Futures Studies.

DALGAARD, K. M., BERGENHOLTZ, H., NIELSEN, M. E. & TIMM, H. 2014. Early integration of palliative care in hospitals: A systematic review on methods, barriers, and outcome. *Palliative and Supportive Care*, 12, 495-513.

DANERMARK, B., EKSTROM, M., JAKOBSEN, L. & KARLSSON, J. C. 2002. *Explaining Society: An Introduction to Critical Realism in the Social Sciences*, London: Routledge.

DATA PROTECTION ACT 2018 *c.12*. UK Government.

DAVIES, J. M., GAO, W., SLEEMAN, K. E., LINDSEY, K., MURTAGH, F. E., TENO, J. M., DELIENS, L., WEE, B., HIGGINSON, I. J. & VERNE, J. 2016. Using routine data to improve palliative and end of life care. *BMJ Supportive & Palliative Care*, 6, 257.

DAVIES, J. M., SLEEMAN, K. E., LENIZ, J., WILSON, R., HIGGINSON, I. J., VERNE, J., MADDOCKS, M. & MURTAGH, F. E. M. 2019. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLoS Medicine*, 16.

DAVIES, J. M., MADDOCKS, M., CHUA, K-C, DEMAKAKOS, P., SLEEMAN, K. E., & MURTAGH, F. E. M. 2021. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. *Lancet Public Health*; 6: e155-63

DAVIES, P., POOL, R. & SMELT, G. 2011. What do we actually know about the referral process? *The British journal of general practice : the journal of the Royal College of General Practitioners*, 61, 752-753.

DEN HERDER-VAN DER EERDEN, M., VAN WIJNGAARDEN, J., PAYNE, S., PRESTON, N., LINGE-DAHL, L., RADBRUCH, L., VAN BEEK, K., MENTEN, J., BUSA, C., CSIKOS, A., VISSERS, K., VAN GURP, J. & HASSELAAR, J. 2018. Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. *Palliative Medicine*, 32, 1091-1102.

DENZIN, N. 2014. Writing and/as Analysis or Performing the World. In: FLICK, U. (ed.) *The Sage Handbook of Qualitative Data Analysis*. London: Sage Publications.

DEPARTMENT OF HEALTH 2008. End of Life Care Strategy. Promoting high quality care for all adults at the end of life. London: Department of Health, UK Government.

DEPARTMENT OF HEALTH 2012. End of Life Care Strategy Fourth Annual Report 'How people die remains in the memory of those who live on'. *End of Life Care Strategy* London: Department of Health, UK Government.

DEPARTMENT OF HEALTH 2016. Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care. London: Department of Health, UK Government.

DESGRANGES, L. & UGARRIZA, D. N. 2000. The Concept of Theme as Used in Qualitative Nursing Research. *Western Journal of Nursing Research*, 22, 351-372.

DHSS 1980. Inequalities in Health: Report of a Research Working Group (The Black Report). London: Department of Health and Social Security (DHSS).

DICKIE, E., HEARTY, W., FRASER, A., MCCARTNEY, G., DOYLE, E. & MYERS, F. 2015. Power - a health and social justice issue? Edinburgh: NHS Health Scotland.

DIGGLE, P., HEAGERTY, P., LIANG, K.-Y. & ZEGER, S. 2013. *Analysis of Longitudinal Data*, Oxford, Oxford University Press.

DIXON, J., KING, D., MATOSEVIC, T., CLARK, M. & KNAPP, M. 2015. Equity in the Provision of Palliative Care in the UK. London: Marie Curie.

DIXON-WOODS, M., CAVERS, D., AGARWAL, S., ANNANDALE, E., ARTHUR, A., HARVEY, J., HSU, R., KATBAMNA, S., OLSEN, R., SMITH, L., RILEY, R. & SUTTON, A. J. 2006. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6, 35.

DIXON-WOODS, M., KIRK, D., AGARWAL, S., ANNANDALE, E., ARTHUR, T., HARVEY, J., HSU, R., KATBAMNA, S., OLSEN, R., SMITH, L., RILEY, R. & SUTTON, A. 2005. Vulnerable groups and access to health care : a critical interpretive review. NHS Service Delivery and Organisation R&D Programme

DODGE, M. & BROOK, R. 2016. *Making Post-War Manchester: Visions of an Unmade City*, Manchester, The Modernist Society.

DOUGLAS, C. 1992. For all the saints. *British Medical Journal*, 304.

DRABBLE, L., TROCKI, K. F., SALCEDO, B., WALKER, P. C. & KORCHA, R. A. 2016. Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qualitative social work : QSW : research and practice*, 15, 118-133.

DUNLEAVY, L., PRESTON, N., BAJWAH, S., BRADSHAW, A., CRIPPS, R., FRASER, L. K., MADDOCKS, M., HOCAOGLU, M., MURTAGH, F. E. M., OLUYASE, A., SLEEMAN, K. E., HIGGINSON, I. & WALSHE, C. 2020. 'Necessity is the mother of invention': Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multi-national survey (CovPall). *medRxiv*, 2020.10.29.20215996.

EASTON, G. 2010. Critical realism in case study research. *Industrial Marketing Management*, 39, 118-128.

ECONOMIST INTELLIGENCE UNIT 2015. The 2015 Quality of Death Index. Ranking palliative care across the world. London: The Economist.

EISENHARDT, K. 2007. Theory Building from Cases: Opportunities and Challenges. *Academy of Management Journal*, 50, 25-32.

ELEY, E., JACKSON, B., BURTON, C. & WALTON, E. 2018. Professional resilience in GPs working in areas of socioeconomic deprivation: a qualitative study in primary care. *British Journal of General Practice*, 68, e819-e825.

ETKIND, S. N., BONE, A. E., GOMES, B., LOVELL, N., EVANS, C. J., HIGGINSON, I. J. & MURTAGH, F. E. M. 2017. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, 15, 102.

EVANS, N., MEÑACA, A., ANDREW, E. V. W., KOFFMAN, J., HARDING, R., HIGGINSON, I. J., POOL, R., GYSELS, M. & 2011. Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy. *BMC Health Services Research*, 11, 141.

EVANS, R., STONE, D. & ELWYN, G. 2003. Organizing palliative care for rural populations: a systematic review of the evidence. *Family Practice*, 20, 304-310.

EXWORTHY, M. & MORCILLO, V. 2019. Primary care doctors' understandings of and strategies to tackle health inequalities: A qualitative study. *Primary Health Care Research & Development*, 20.

FERGUS, C. J. Y., CHINN, D. J. & MURRAY, S. A. 2009. Assessing and improving out-of-hours palliative care in a deprived community: a rapid appraisal study. *Palliative Medicine*, 24, 493-500.

FIRN, J., PRESTON, N. & WALSHE, C. 2015. What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis. *Palliative Medicine*, 30, 240-256.

FISHER, R. F., LASSERSON, D. & HAYWARD, G. 2016. Out-of-hours primary care use at the end of life: a descriptive study. *Br J Gen Pract*, 66, e654-60.

FOSTER, H. M. E., CELIS-MORALES, C. A., NICHOLL, B. I., PETERMANN-ROCHA, F., PELL, J. P., GILL, J. M. R., O'DONNELL, C. A. & MAIR, F. S. 2018. The effect of socioeconomic deprivation on the association between an extended measurement of unhealthy lifestyle factors and health outcomes: a prospective analysis of the UK Biobank cohort. *The Lancet Public Health*, 3, e576-e585.

GALOBARDES, B., LYNCH, J. & SMITH, G. D. 2007. Measuring socioeconomic position in health research. *British Medical Bulletin*, 81-82, 21-37.

GARDINER, C., GOTTF, M. & INGLETON, C. 2012. Factors supporting good partnership working between generalist and specialist palliative care services: A systematic review. *British Journal of General Practice*, 62, e353-62.

GARNER, S. & BHATTACHARYYA, G. 2011. Poverty, ethnicity and place. York: Joseph Rowntree Foundation.

GATRELL, A. C. & WOOD, D. J. 2012. Variation in geographic access to specialist inpatient hospices in England and Wales. *Health & Place*, 18, 832-840.

GIESBRECHT, M., STAJDUHAR, K. I., MOLLISON, A., PAULY, B., REIMER-KIRKHAM, S., MCNEIL, R., WALLACE, B., DOSANI, N. & ROSE, C. 2018. Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Health & Place*, 53, 43-51.

GKIOULEKA, A., HUIJTS, T., BECKFIELD, J. & BAMBRA, C. 2018. Understanding the micro and macro politics of health: Inequalities, intersectionality & institutions - A research agenda. *Social Science & Medicine*, 200, 92-98.

GMC 2013. Good medical practice. Manchester: General Medical Council (GMC).

GÓMEZ-VÍRSEDA, C., DE MAESENEER, Y. & GASTMANS, C. 2019. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC medical ethics*, 20, 76-76.

GOTT, M., INGLETON, C., BENNETT, M. I. & GARDINER, C. 2011. Transitions to palliative care in acute hospitals in England: qualitative study. *British Medical Journal*, 342.

GOTT, M., MORGAN, T. & WILLIAMS, L. 2020. Gender and palliative care: a call to arms. *Palliative Care and Social Practice*, 14, 2632352420957997.

GOTT, M. & ROBINSON, J. 2018. Are we getting it wrong? Perspectives on the future of palliative care in hospitals. *Palliative Medicine*, 0269216318809539.

GRAHAM, H. 2007. *Unequal Lives. Health and Socio-economic Inequalities*, Maidenhead, Open University Press.

GRANDE, G. E., ADDINGTON-HALL, J. M. & TODD, C. J. 1998. Place of death and access to home care services: are certain patient groups at a disadvantage? *Social Science & Medicine*, 47, 565-579.

GRANT, M., BACK, A. & DETTMAR, N. 2020. Public Perceptions of Advance Care Planning, Palliative Care, and Hospice: A Scoping Review. *Journal of Palliative Medicine*, 24.

GREENER, I. 2007. Are the assumptions underlying patients choice realistic?: a review of the evidence. *British Medical Bulletin*, 83, 249-258.

GRINDROD, A. 2020. Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life. *Progress in Palliative Care*, 28, 94-100.

GROFF, R. 2004. *Critical Realism, Post-positivism and the Possibility of Knowledge*, Abingdon, Oxon: Routledge.

GRUEN, R. L., PEARSON, S. D. & BRENNAN, T. A. 2004. Physician-Citizens—Public Roles and Professional Obligations. *Jama*, 291, 94-98.

GUETTERMAN, T. C. & FETTERS, M. D. 2018. Two Methodological Approaches to the Integration of Mixed Methods and Case Study Designs: A Systematic Review. *American Behavioral Scientist*, 62, 900-918.

GULLIFORD, M., MORGAN, M., HUGHES, D., BEECH, R., FIGEROA-MUNOZ, J., GIBSON, B., HUDSON, M., ARUMUGAM, C., CONNELL, P., MOHIDDIN, A. & SEDGWICK, J. 2001. Access to Health Care Report of a Scoping Exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). London: Kings College London.

HANRATTY, B., GOLDACRE, M., GRIFFITH, M., WHITEHEAD, M. & CAPEWELL, S. 2008a. Making the most of routine data in palliative care research – a case study analysis of linked hospital and mortality data on cancer and heart failure patients in Scotland and Oxford. *Palliative Medicine*, 22, 744-749.

HANRATTY, B. & HOLMES, L. 2011. Social Inequality in Dying. In: OLIVIERE, D., MONROE, B. & PAYNE, S. (eds.) *Death, Dying, and Social Differences*. Oxford: Oxford University Press.

HANRATTY, B., HOLMES, L., LOWSON, E., GRANDE, G., ADDINGTON-HALL, J., PAYNE, S. & SEYMOUR, J. 2012. Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. *Journal of pain and symptom management*, 44, 74-83.

HANRATTY, B., JACOBY, A. & WHITEHEAD, M. 2008b. Socioeconomic differences in service use, payment and receipt of illness-related benefits in the last year of life: findings from the British Household Panel Survey. *Palliative Medicine*, 22, 248-255.

HARRISON, N., CAVERS, D., CAMPBELL, C. & MURRAY, S. A. 2012. Are UK primary care teams formally identifying patients for palliative care before they die? *British Journal of General Practice*, 62, e344.

HART, T. 1971. The Inverse Care Law. *The Lancet*, 297, 405-412.

HASEGAWA, H., REILLY, D., MERCER, S. W. & BIKKER, A. P. 2005. Holism in primary care: the views of Scotland's general practitioners. *Primary Health Care Research & Development*, 6, 320-328.

HASSELAAR, J. & PAYNE, S. 2016. Integrated palliative care. Nijmegen, the Netherlands: Radboud University Medical Center.

HAWKER, S., PAYNE, S., KERR, C., HARDEY, M. & POWELL, J. 2002. Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research*, 12, 1284-1299.

HENRY, C., FINDLAY, H., LEECH, I., CAWLEY, L., CHADHA, S., PORTEUS, J., BLACKBURN, S., CHAPMAN, S., HOBDAY, M., ELLIS, J., RAO, P., MCCARVILL, P., BROOKS, D. D., ALLBERRY, J., CHEESLEY, A., NIGHTINGALE, D. P., DIXON, R., VERNE, P. J. & HAYES, A. 2015. A Review of Choice in End of Life Care. The Choice in End of Life Care Programme Board.

HICKEY, D. & QUINN, S. 2012. 'I don't want to talk about it.' Raising public awareness of end-of-life care planning in your locality. *International Journal of Palliative Nursing*, 18, 241-247.

HIGGINSON, I. J., SHIPMAN, C., GYSELS, M., WHITE, P., BARCLAY, S., FORREST, S., WORTH, A., MURRAY, S., SHEPHERD, J., DALE, J., DEWAR, S., PETERS, M., WHITE, S., RICHARDSON, A., HOTOPF, M., LORENZ, K. & KOFFMAN, J. 2007. Scoping exercise on generalist services for adults at the end of life: research, knowledge, policy and future research needs. Report 1: Overview and recommendations for future research in generalist end of life care. London: National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO).

HO, A. 2008. The Individualist Model of Autonomy and the Challenge of Disability. *Journal of Bioethical Inquiry*, 5, 193-207.

HOARE, S., KELLY, M. P. & BARCLAY, S. 2019. Home care and end-of-life hospital admissions: a retrospective interview study in English primary and secondary care. *British Journal of General Practice*, 69, e561.

HOSPICE UK 2016. Hospice Care in the UK 2016 - scope, scale, and opportunities. London: Hospice UK.

HOSPICE UK 2017a. Hospice care in the UK 2017. From numbers to insight. London: Hospice UK.

HOSPICE UK. 2017b. *Only three in five Britons know that hospice care is free new survey shows* [Online]. Available: <https://www.hospiceuk.org/about-hospice-care/media-centre/press-releases/details/2017/10/09/only-three-in-five-britons-know-that-hospice-care-is-free-new-survey-shows> [Accessed 01 August 2019].

HOSPICE UK. 2019. *Rising costs and precarious "Jenga-like" funding model undermining capacity of hospices to meet demand for care* [Online]. Hospice UK. Available: <https://www.hospiceuk.org/about-hospice-care/media-centre/press-releases/details/2019/05/07/rising-costs-and-precarious-jenga-like-funding-model-undermining-capacity-of-hospices-to-meet-demand-for-care> [Accessed 4 September 2020].

HOSPICE UK. 2020a. *Hospice UK responds to the ITV News report on hospice funding* [Online]. Hospice UK. [Accessed 10 December 2020].

HOSPICE UK. 2020b. *Our definition of hospice care* [Online]. Available: <https://www.hospiceuk.org/about-us/our-definition-of-hospice-care> [Accessed 01 December 2020].

HOWELL, D., HARDY, B., BOYD, C., WARD, C., ROMAN, E. & JOHNSON, M. 2014. Community palliative care clinical nurse specialists: a descriptive study of nurse-patient interactions. *International Journal of Palliative Nursing*, 20, 246-253.

HUDSON, B. F., FLEMMING, K., SHULMAN, C. & CANDY, B. 2016. Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care*, 15, 96.

HUGHES, A., GUDMUNDSDOTTIR, M. & DAVIES, B. 2007. Everyday Struggling to Survive: Experience of the Urban Poor Living With Advanced Cancer. *Oncology Nursing Society*, 34, 1113-1118.

HUI, D., MENG, Y. C., BRUERA, S., GENG, Y., HUTCHINS, R., MORI, M., STRASSER, F. & BRUERA, E. 2016. Referral Criteria for Outpatient Palliative Cancer Care: A Systematic Review. *Oncologist*, 21, 895-901.

HUNTER, C., CHEW-GRAHAM, C., LANGER, S., STENHOFF, A., DRINKWATER, J., GUTHRIE, E. & SALMON, P. 2013. A qualitative study of patient choices in using emergency health care for long-term conditions: the importance of candidacy and recursivity. *Patient Education and Counseling*, 93, 335-341.

INFORMATION COMMISSIONER'S OFFICE 2018. Guide to the UK General Data Protection Regulation (UK GDPR). England: Information Commissioner's Office (ICO).

JARMAN, B. 1983. Identification of underprivileged areas. *British Medical Journal (Clinical Research Ed)*, 286, 1705-1708.

JOHNSON, M. J., ALLGAR, V., CHEN, H., DUNN, L., MACLEOD, U. & CURROW, D. C. 2017. The complex relationship between household income of family caregivers, access to palliative care services and place of death: A national household population survey. *Palliative Medicine*, 32, 357-365.

JOHNSON, R. B., ONWUEGBUZIE, A. J. & TURNER, L. A. 2007. Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1, 112-133.

JONES, G., MEEGAN, R., KENNETT, P. & CROFT, J. 2015. The uneven impact of austerity on the voluntary and community sector: A tale of two cities. *Urban Studies*, 53, 2064-2080.

KESSLER, D., PETERS, T. J., LEE, L. & PARR, S. 2005. Social class and access to specialist palliative care services. *Palliative Medicine*, 19, 105-110.

KIRBY, E., BROOM, A. & GOOD, P. 2014. The role and significance of nurses in managing transitions to palliative care: a qualitative study. *BMJ Open*, 4, e006026.

KIRKWOOD, B. R. & STERNE, J. A. C. 2003. *Essential Medical Statistics*, Hoboken: John Wiley & Sons, Incorporated.

KOEHN, S. 2009. Negotiating candidacy: ethnic minority seniors' access to care. *Ageing and society*, 29, 585-608.

KOFFMAN, J., BURKE, G., DIAS, A., RAVAL, B., BYRNE, J., GONZALES, J. & DANIELS, C. 2007. Demographic factors and awareness of palliative care and related services. *Palliative Medicine*, 21, 145-153.

KOVANDŽIĆ, M., CHEW-GRAHAM, C., REEVE, J., EDWARDS, S., PETERS, S., EDGE, D., ASEEM, S., GASK, L. & DOWRICK, C. 2011. Access to primary mental health care for hard-

to-reach groups: From 'silent suffering' to 'making it work'. *Social Science & Medicine*, 72, 763-772.

KRIEGER, N. 2001. A glossary for social epidemiology. *Journal of Epidemiology and Community Health*, 55, 693-700.

KRISTJANSON, L. J. & AOUN, S. 2004. Palliative Care for Families: Remembering the Hidden Patients. *The Canadian Journal of Psychiatry*, 49, 359-365.

LAWRANCE, C. 2020. Death: a social disadvantage? How one hospice is addressing inequality at end of life. *Primary Health Care*, 30, 23-27.

LEVESQUE, J.-F. 2006. *Inequalities in access to health care in urban south India*. PhD, Université de Montréal.

LEVESQUE, J.-F., HARRIS, M. F. & RUSSELL, G. 2013. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12, 18.

LEWIS, J. M., DIGIACOMO, M., CURROW, D. C. & DAVIDSON, P. M. 2011. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *Journal of Pain and Symptom Management*, 42, 105-118.

LEWIS, J. M., DIGIACOMO, M., CURROW, D. C. & DAVIDSON, P. M. 2014. Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations. *BMC Palliative Care*, 13, 30.

LLANWARNE, N., NEWBOULD, J., BURT, J., CAMPBELL, J. L. & ROLAND, M. 2017. Wasting the doctor's time? A video-elicitation interview study with patients in primary care. *Social Science & Medicine*, 176, 113-122.

LOLICH, L. & LYNCH, K. 2017. No Choice without Care: Palliative Care as a Relational Matter, the Case of Ireland. *Soundings: An Interdisciplinary Journal*, 100, 353-374.

LONDON CANCER ALLIANCE 2015. A review of Specialist Palliative Care provision and access across London. Mapping the capital. London: London Cancer Alliance (LCA); PalIE8; Marie Curie.

LYNCH, J. & KAPLAN, G. 2000. Socioeconomic Position. In: BERKMAN, L. & KAWACHI, I. (eds.) *Social Epidemiology*. New York: Oxford University Press.

MABRY, L. 2012. Case Study in Social Research In: ALASUUTARI, P., BICKMAN, L. & BRANNEN, J. (eds.) *The SAGE Handbook of Social Research Methods*. London: SAGE Publications.

MACDONALD, S., BLANE, D., BROWNE, S., CONWAY, E., MACLEOD, U., MAY, C. & MAIR, F. 2016. Illness identity as an important component of candidacy: Contrasting experiences of help-seeking and access to care in cancer and heart disease. *Social Science & Medicine*, 168, 101-110.

MACKENZIE, M., CONWAY, E., HASTINGS, A., MUNRO, M. & O'DONNELL, C. A. 2013. Is 'Candidacy' a Useful Concept for Understanding Journeys through Public Services? A Critical Interpretive Literature Synthesis. *Social Policy & Administration*, 47, 806-825.

MACKENZIE, M., GANNON, M., STANLEY, N., COSGROVE, K. & FEDER, G. 2019. 'You certainly don't go back to the doctor once you've been told, "I'll never understand women like you.'" Seeking candidacy and structural competency in the dynamics of domestic abuse disclosure. *Sociology of Health and Illness*, 41, 1159-1174.

MACKENZIE, M., SKIVINGTON, K. & FERGIE, G. 2020. "The state They're in": Unpicking fantasy paradigms of health improvement interventions as tools for addressing health inequalities. *Social Science & Medicine*, 256, 113047.

MACKENZIE, M., TURNER, F., PLATT, S., REID, M., WANG, Y., CLARK, J., SRIDHARAN, S. & O'DONNELL, C. A. 2011. What is the 'problem' that outreach work seeks to address and how might it be tackled? Seeking theory in a primary health prevention programme. *BMC Health Services Research*, 11, 350.

MAHASE, E. 2020. Covid-19: Charity cuts could put the NHS under even more pressure. *BMJ*.

MARIE CURIE 2014. Death and dying in Wales. Marie Curie Cancer Care and the Bevan Foundation.

MARIE CURIE. 2018. *What are palliative care and end of life care?* [Online]. Available: <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care> [Accessed 20 March 2019].

MARMOT, M. 2010. Fair Society: Health Lives. The Marmot Review. *Strategic Review of Health Inequalities in England post-2010*. Institute of Health Equity.

MARMOT, M. 2015. The health gap: the challenge of an unequal world. *The Lancet*, 385, 2442-44.

MARMOT, M. 2017. Social justice, epidemiology and health inequalities. *European Journal of Epidemiology*, 32, 537-546.

MARMOT, M., ALLEN, J., BOYCE, T., GOLDBLATT, P. & MORRISON, J. 2020. Health Equity in England: The Marmot Review 10 Years On. Institute of Health Equity.

MARMOT, M. & BELL, R. 2012. Fair society, healthy lives. *Public Health*, 126 S4-S10.

MARTIN, D., MILLER, A. P., QUESNEL-VALLÉE, A., CARON, N. R., VISSANDJÉE, B. & MARCHILDON, G. P. 2018. Canada's universal health-care system: achieving its potential. *The Lancet*, 391, 1718-1735.

MASON, B., BUCKINGHAM, S., FINUCANE, A., HUTCHISON, P., KENDALL, M., MCCUTCHEON, H., PORTEOUS, L. & MURRAY, S. A. 2015. Improving primary palliative care in Scotland: Lessons from a mixed methods study. *BMC Family Practice*, 16.

MASSON, J. D. 2002. Non-professional perceptions of 'good death': A study of the views of hospice care patients and relatives of deceased hospice care patients. *Mortality*, 7, 191-209.

MCEVOY, P. & RICHARDS, D. 2006. A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research in Nursing*, 11, 66-78.

MCMAHON, N. 2019. *Working 'upstream' to reduce health inequalities: a Foucauldian discourse analysis*. PhD, University of Central Lancashire.

MCNAMARA, B. 2004. Good enough death: Autonomy and choice in Australian palliative care. *Social Science & Medicine*, 58, 929-938.

MEAD, R., THURSTON, M. & BLOYCE, D. 2020. From public issues to personal troubles: individualising social inequalities in health within local public health partnerships. *Critical Public Health*, 1-13.

MEIER, D. E. 2011. Increased access to palliative care and hospice services: opportunities to improve value in health care. *The Milbank quarterly*, 89, 343-380.

MERCER, S. W. & WATT, G. C. M. 2007. The inverse care law: clinical primary care encounters in deprived and affluent areas of Scotland. *Annals of family medicine*, 5, 503-510.

MERRIAM, S. & TISDELL, E. 2015. *Qualitative research: a guide to design and implementation*, Newark: Wiley.

MERTON, R. 1968. *Social Theory and Social Structure*, New York, Free Press.

METHLEY, A. M., CHEW-GRAHAM, C. A., CHERAGHI-SOHI, S. & CAMPBELL, S. M. 2017. A qualitative study of patient and professional perspectives of healthcare services for multiple sclerosis: implications for service development and policy. *Health & Social Care in the Community*, 25, 848-857.

METZL, J. M. & HANSEN, H. 2014. Structural competency: theorizing a new medical engagement with stigma and inequality. *Social Science & Medicine*, 103, 126-133.

MIESFELDT, S., MURRAY, K., LUCAS, L., CHANG, C.-H., GOODMAN, D. & MORDEN, N. E. 2012. Association of Age, Gender, and Race with Intensity of End-of-Life Care for Medicare Beneficiaries with Cancer. *Journal of Palliative Medicine*, 15, 548-554.

MILBOURNE, P. 2014. Poverty, place, and rurality: Material and sociocultural disconnections. *Environment and Planning A: Economy and Space*, 46, 566-580.

MILES, M. B. & HUBERMAN, A. M. 1994. *Qualitative data analysis: An expanded sourcebook*, Sage Publications.

MILNE, A. 2020. UK under fire for suggesting coronavirus ‘great leveller’. *Thomson Reuters Foundation*.

MINISTRY OF HOUSING, COMMUNITIES AND LOCAL GOVERNMENT, 2019a. The English Indices of Deprivation 2019. Research report. London: Ministry of Housing, Communities and Local Government, UK Government.

MINISTRY OF HOUSING, COMMUNITIES AND LOCAL GOVERNMENT, 2019b. The English Indices of Deprivation 2019. Statistical Release. London: Ministry of Housing, Communities and Local Government.

MINISTRY OF HOUSING, COMMUNITIES AND LOCAL GOVERNMENT, 2019c. File 1: index of multiple deprivation. London: Ministry of Housing, Communities and Local Government, UK Government.

MINISTRY OF HOUSING, COMMUNITIES AND LOCAL GOVERNMENT., 2019d. *Indices of Deprivation 2019 explorer (postcode mapper)* [Online]. Available: [https://dclgapps.communities.gov.uk/imd/iod\\_index.html](https://dclgapps.communities.gov.uk/imd/iod_index.html) [Accessed 10 April 2020].

MOLLER, D. 2010. *Portraits of the invisible: Faces of urban dying poor*, Oxford, Oxford University Press.

MOORE, A., CARTER, B., HUNT, A. & SHEIKH, K. 2013. 'I am closer to this place'—Space, place and notions of home in lived experiences of hospice day care. *Health & Place*, 19, 151-158.

MORGAN, T., ANN WILLIAMS, L., TRUSSARDI, G. & GOT, M. 2016. Gender and family caregiving at the end-of-life in the context of old age: A systematic review. *Palliative Medicine*, 30, 616-624.

MRIG, E. H. & SPENCER, K. L. 2018. Political economy of hope as a cultural facet of biomedicalization: A qualitative examination of constraints to hospice utilization among U.S. end-stage cancer patients. *Social Science & Medicine*, 200, 107-113.

MUELLER, A. L., MCNAMARA, M. S. & SINCLAIR, D. A. 2020. Why does COVID-19 disproportionately affect older people? *Aging*, 12, 9959-9981.

MULLICK, A., MARTIN, J. & SALLNOW, L. 2013. An introduction to advance care planning in practice. *British Medical Journal*, 347.

MURTAGH, F. E. M., BAUSEWEIN, C., VERNE, J., GROENEVELD, E. I., KALOKI, Y. E. & HIGGINSON, I. J. 2013. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, 28, 49-58.

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION 2020. NHPCO Facts and Figures. Virginia: National Hospice and Palliative Care Organization (NHPCO).

NATIONAL PALLIATIVE AND END OF LIFE CARE PARTNERSHIP 2015. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. UK: The National Palliative and End of Life Care Partnership.

NEDJAT-HAIEM, F., CARRION IV, CRIBBS K & LORENZ K 2013. Advocacy at the End of Life: Meeting the Needs of Vulnerable Latino Patients. *Social Work in Health Care*, 52, 558-577.

NEERGAARD, M. A., JENSEN, A. B., OLESEN, F. & VEDSTED, P. 2013. Access to Outreach Specialist Palliative Care Teams among Cancer Patients in Denmark. *Journal of Palliative Medicine*, 16, 951-957.

NOVICK, G. 2008. Is there a bias against telephone interviews in qualitative research? *Research in nursing & health*, 31, 391-398.

O'BRIEN, R., WYKE, S., GUTHRIE, B., WATT, G. & MERCER, S. 2010. An 'endless struggle': a qualitative study of general practitioners' and practice nurses' experiences of managing multimorbidity in socio-economically deprived areas of Scotland. *Chronic Illness*, 7, 45-59.

O'MAHONY, S., MCHENRY, J., SNOW, D., CASSIN, C., SCHUMACHER, D. & SELWYN, P. A. 2008. A review of barriers to utilization of the medicare hospice benefits in urban populations

and strategies for enhanced access. *Journal of urban health : bulletin of the New York Academy of Medicine*, 85, 281-290.

O'CONNOR, S. 2007. Development of Hospice and Palliative Care in the United States. *Omega*, 56, 89-99.

OECHSLE, K., ULLRICH, A., MARX, G., BENZE, G., HEINE, J., DICKEL, L.-M., ZHANG, Y., WOWRETZKO, F., WENDT, K. N., NAUCK, F., BOKEMEYER, C. & BERGELT, C. 2019. Psychological burden in family caregivers of patients with advanced cancer at initiation of specialist inpatient palliative care. *BMC Palliative Care*, 18, 102.

OLIVER, A. & MOSSIALOS, E. 2004. Equity of access to health care: Outlining the foundations for action. *Journal of Epidemiology and Community Health*, 58, 655-658.

OLIVER, D. 2020. David Oliver: Let's be open and honest about covid-19 deaths in care homes. *BMJ*, 369.

ONS. 2017. *How does deprivation vary by leading cause of death? Analysis into how deprivation impacts cause of death in England and Wales*. [Online]. London: Office for National Statistics (ONS). [Accessed 01 February 2019].

ORSINI, M., TRETARRE, B., DAURÈS, J. P. & BESSAOUD, F. 2016. Individual socioeconomic status and breast cancer diagnostic stages: A French case-control study. *European Journal of Public Health*, 26, 445-450.

ØVERSVEEN, E., RYDLAND, H. T., BAMBRA, C. & EIKEMO, T. A. 2017. Rethinking the relationship between socio-economic status and health: Making the case for sociological theory in health inequality research. *Scandinavian Journal of Public Health*, 45, 103-112.

OVERY, C. & TANSEN, E. 2013. Palliative Medicine in the UK c.1970–2010 *Witness Seminar*. Queen Mary, University of London.

PAPARINI, S., GREEN, J., PAPOUTSI, C., MURDOCH, J., PETTICREW, M., GREENHALGH, T., HANCKEL, B. & SHAW, S. 2020. Case study research for better evaluations of complex interventions: rationale and challenges. *BMC Medicine*, 18, 301.

PASK, S., PINTO, C., BRISTOWE, K., VAN VLIET, L., NICHOLSON, C., EVANS, C. J., GEORGE, R., BAILEY, K., DAVIES, J. M., GUO, P., DAVESON, B. A., HIGGINSON, I. J. & MURTAGH, F. E. M. 2018. A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliative Medicine*, 32, 1078-1090.

PATEL, J. A., NIELSEN, F. B. H., BADIANI, A. A., ASSI, S., PATEL, B., RAVINDRANE, R. & WARDLE, H. 2020. Poverty, inequality and COVID-19: the forgotten vulnerable. *Public Health*, 183, 110-111.

PAYNE, M. 2012. Poverty and finance. In: OLIVIERE, D., MONROE, B. & PAYNE, S. (eds.) *Death, Dying, and Social Differences*. Oxford: Oxford University Press.

PAYNE, S., EASTHAM, R., HUGHES, S., VAREY, S., HASSELAAR, J. & PRESTON, N. 2017. Enhancing integrated palliative care: what models are appropriate? A cross-case analysis. 2017/11/29 ed.

PEACOCK, M., BISSELL, P. & OWEN, J. 2014. Dependency denied: Health inequalities in the neo-liberal era. *Social Science & Medicine*, 118, 173-180.

PECHANSKY, R. & THOMAS, J. 1981. The concept of access: definition and relationship to consumer satisfaction. *Medical Care*, 18, 127-40.

PHELAN, J. C., LINK, B. G., DIEZ-ROUX, A., KAWACHI, I. & LEVIN, B. 2004. "Fundamental Causes" of Social Inequalities in Mortality: A Test of the Theory. *Journal of Health and Social Behavior*, 45, 265-285.

POPAY, J., ROBERTS, H., SOWDEN, A., PETTICREW, M., ARAI, L., RODGERS, M., BRITTEN, N., ROEN, K. & DUFFU, S. 2006. Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. A Product from the ESRC Methods Programme. Lancaster: Lancaster University.

POPAY, J., THOMAS, C., WILLIAMS, G., BENNETT, S., GATRELL, A. & BOSTOCK, L. 2003. A proper place to live: health inequalities, agency and the normative dimensions of space. *Social Science & Medicine*, 57, 55-69.

PUBLIC HEALTH ENGLAND. 2019. *Palliative and end of life care: hospital deaths 2006 to 2017* [Online]. Public Health England. Available: <https://www.gov.uk/government/publications/palliative-and-end-of-life-care-hospital-deaths-2006-to-2017/palliative-and-end-of-life-care-hospital-deaths-2006-to-2017> [Accessed 11 July 2019].

PUBLIC HEALTH ENGLAND 2020. Inhale - INteractive Health Atlas of Lung conditions in England. Public Health England.

RADBRUCH, L., DE LIMA, L., KNAUL, F., WENK, R., ALI, Z., BHATNAGHAR, S., BLANCHARD, C., BRUERA, E., BUITRAGO, R., BURLA, C., CALLAWAY, M., MUNYORO, E. C., CENTENO, C., CLEARY, J., CONNOR, S., DAVAASUREN, O., DOWNING, J., FOLEY, K., GOH, C., GOMEZ-GARCIA, W., HARDING, R., KHAN, Q. T., LARKIN, P., LENG, M., LUYIRIKA, E., MARSTON, J., MOINE, S., OSMAN, H., PETTUS, K., PUCHALSKI, C., RAJAGOPAL, M. R., SPENCE, D., SPRUIJT, O., VENKATESWARAN, C., WEE, B., WOODRUFF, R., YONG, J. & PASTRANA, T. 2020. Redefining Palliative Care—A New Consensus-Based Definition. *Journal of Pain and Symptom Management*, 60, 754-764.

RAE, A., HAMILTON, R., CRISP, R. & POWELL, R. 2018. Overcoming deprivation and disconnection in UK cities. York: Joseph Rowntree Foundation.

RAIKES, L., GIOVANNINI, A. & GETZEL, B. 2019. Divided and connected. Regional inequalities in the North, the UK, and the Developed World. The State of the North 2019. *State of the North*. Institute for Public Policy Research.

RANDALL, F. & DOWNIE, R. S. 2006. *The Philosophy of Palliative Care: Critique and Reconstruction*, Oxford, Oxford University Press.

RAPHAEL, D. 2011. A discourse analysis of the social determinants of health. *Critical Public Health*, 21, 221-236.

REES-ROBERTS, M., WILLIAMS, P., HASHEM, F., BRIGDEN, C., GREENE, K., GAGE, H., GOODWIN, M., SILSBURY, G., WEE, B., BARCLAY, S., WILSON, P. M. & BUTLER, C.

2019. Hospice at Home services in England: a national survey. *BMJ Supportive & Palliative Care*, bmjspcare-2019-001818.

REIMER-KIRKHAM, S., STAJDUHAR, K., PAULY, B., GIESBRECHT, M., MOLLISON, A., MCNEIL, R. & WALLACE, B. 2016. Death is a social justice issue: Perspectives on equity-informed palliative care. *Advances in Nursing Sciences*, 39, 293-307.

RIFFENBURGH, R. H. 2012. *Statistics in medicine*, Amsterdam, Elsevier/Academic Press.

ROBINSON, J., GOTTFRIED, M., FREY, R., GARDINER, C. & INGLETON, C. 2017. Predictors of patient-related benefit, burden and feeling safe in relation to hospital admissions in palliative care: A cross-sectional survey. *Palliative Medicine*, 32, 167-171.

ROBINSON, J., GOTTFRIED, M., GARDINER, C. & INGLETON, C. 2016. The 'problematisation' of palliative care in hospital: an exploratory review of international palliative care policy in five countries. *BMC Palliative Care*, 15, 64.

ROBINSON, J., GOTTFRIED, M. & INGLETON, C. 2013. Patient and family experiences of palliative care in hospital: What do we know? An integrative review. *Palliative Medicine*, 28, 18-33.

ROBSON, C. 2016. *Real world research : a resource for users of social research methods in applied settings*.

ROGERS, A., HASSELL, K. & NICOLAAS, G. 1999. *Demanding patients? Analysing the use of primary care*, Buckingham, Open University Press.

ROSE, G., KHAW, K. & MARMOT, M. 2008. *Rose's strategy of preventive medicine*, Oxford, Oxford University Press.

ROSENWAX, L. K., MCNAMARA, B., BLACKMORE, A. M. & HOLMAN, C. D. J. 2005. Estimating the size of a potential palliative care population. *Palliative Medicine*, 19, 556-562.

ROYAL COLLEGE OF PHYSICIANS 2016. End of Life Care Audit - Dying in Hospital: executive summary. London: Royal College of Physicians (RCP).

SAFFORD, M. M., ALLISON, J. J. & KIEFE, C. I. 2007. Patient Complexity: More Than Comorbidity. The Vector Model of Complexity. *Journal of General Internal Medicine*, 22, 382-390.

SALINS, N., GHOSHAL, A., HUGHES, S. & PRESTON, N. 2020. How views of oncologists and haematologists impacts palliative care referral: a systematic review. *BMC Palliative Care*, 19, 175.

SANTOS SALAS, A., WATANABE, S. M., TARUMI, Y., WILDEMAN, T., HERMOSA GARCIA, A. M., ADEWALE, B. & DUGGLEBY, W. 2019. Social disparities and symptom burden in populations with advanced cancer: specialist palliative care providers' perspectives. *Supportive Care in Cancer*, 27, 4733-4744.

SAVAGE, M., DEVINE, F., CUNNINGHAM, N., TAYLOR, M., LI, Y., HJELLBREKKE, J., LE ROUX, B., FRIEDMAN, S. & MILES, A. 2013. A New Model of Social Class? Findings from the BBC's Great British Class Survey Experiment. *Sociology*, 47, 219-250.

SAYER, R. A. 2000. *Realism and social science*, London, SAGE.

SCHAPMIRE, T. J., HEAD, B. A. & FAUL, A. C. 2012. Just Give Me Hope: Lived Experiences of Medicaid Patients With Advanced Cancer. *Journal of Social Work in End-of-Life and Palliative Care*, 8, 29-52.

SCHOCKETT, E. R., TENO, J. M. & MILLER, S. C. S., BRAD 2005. Late referral to hospice and bereaved family member perception of quality of end-of-life care. *Journal of Pain and Symptom Management*, 30, 400-407.

SCHOFIELD, P., CAREY, M., LOVE, A., NEHILL, C. & WEIN, S. 2006. 'Would you like to talk about your future treatment options?' discussing the transition from curative cancer treatment to palliative care. *Palliative Medicine*, 20, 397-406.

SCHUURMAN, N., MARTIN, M., CROOKS, V. A. & RANDALL, E. 2018. The development of a spatial palliative care index instrument for assessing population-level need for palliative care services. *Health & Place*, 49, 50-58.

SEAL, K., MURRAY, C. D. & SEDDON, L. 2015. The experience of being an informal "carer" for a person with cancer: A meta-synthesis of qualitative studies. *Palliative and Supportive Care*, 13, 493-504.

SEALE, C., ADDINGTON-HALL, J. & MCCARTHY, M. 1997. Awareness of dying: prevalence, causes and consequences. *Social Science & Medicine*, 45, 477-484.

SEN, A. 1985. Well-being, Agency and Freedom: The Dewey Lectures 1984. *Journal of Philosophy*, 82.

SEN, A. 1995. *Inequality Reexamined*, Oxford University Press.

SEYMOUR, J. 2012. Looking back, looking forward: the evolution of palliative and end-of-life care in England. *Mortality*, 17, 1-17.

SHALEV, A., PHONGTANKUEL, V., KOZLOV, E., SHEN, M. J., ADELMAN, R. D. & REID, M. C. 2017. Awareness and Misperceptions of Hospice and Palliative Care: A Population-Based Survey Study. *American Journal of Hospice and Palliative Medicine*, 35, 431-439.

SIMONS, H. 1996. The paradox of case study. *Cambridge Journal of Education*, 26, 225.

SIMONS, H. 2009. *Case study research in practice*, London, SAGE.

SLEEMAN, K. E., DAVIES, J. M., VERNE, J., GAO, W. & HIGGINSON, I. J. 2016. The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012. *Palliative Medicine*, 30, 45-53.

SMITH, M. J. & LIEHR, P. R. 2013. *Middle Range Theory for Nursing : Third Edition*, New York, Springer Publishing Company.

SPENCER, K. L., HAMMAD MRIG, E., MATLOCK, D. D. & KESSLER, E. R. 2017. A Qualitative Investigation of Cross-domain Influences on Medical Decision Making and the Importance of Social Context for Understanding Barriers to Hospice Use. *Journal of Applied Social Science*, 11, 48-59.

SPILSBURY, K., ROSENWAX, L., ARENDTS, G. & SEMMENS, J. B. 2017. The Association of Community-Based Palliative Care With Reduced Emergency Department Visits in the Last Year of Life Varies by Patient Factors. *Annals of Emergency Medicine*, 69, 416-425.

SPRUYT, O. 1999. Community-based palliative care for Bangladeshi patients in east London. Accounts of bereaved carers. *Palliative Medicine*, 13, 119-129.

STAJDUHAR, K. I., GIESBRECHT, M., MOLLISON, A. & D'ARCHANGELO, M. 2020. "Everybody in this community is at risk of dying": An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings. *Palliative and Supportive Care*, 18, 670-675.

STAJDUHAR, K. I., MOLLISON, A., GIESBRECHT, M., MCNEIL, R., PAULY, B., REIMER-KIRKHAM, S., DOSANI, N., WALLACE, B., SHOWLER, G., MEAGHER, C., KVAKIC, K., GLEAVE, D., TEAL, T., ROSE, C., SHOWLER, C. & ROUNDS, K. 2019. "Just too busy living in the moment and surviving": barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, 18, 11.

STAKE, R. E. 2006. *Multiple case study analysis*, The Guilford Press.

STURGES, J. E. & HANRAHAN, K. J. 2004. Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. *Qualitative Research*, 4, 107-118.

TARRANT, C., WINDRIDGE, K., BAKER, R., FREEMAN, G. & BOULTON, M. 2015. 'Falling through gaps': primary care patients' accounts of breakdowns in experienced continuity of care. *Family practice*, 32, 82-87.

TAYLOR, R., ELLIS, J., GAO, W., SEARLE, L., HEAPS, K., DAVIES, R., HAWKSWORTH, C., GARCIA-PEREZ, A., COLCLOUGH, G., WALKER, S. & WEE, B. 2020. A scoping review of initiatives to reduce inappropriate or non-beneficial hospital admissions and bed days in people nearing the end of their life: much innovation, but limited supporting evidence. *BMC Palliative Care*, 19, 24.

TOMISON, G. & McDOWELL, J. R. S. 2011. Nurses' needs in delivering palliative care for long-term conditions. *British Journal of Community Nursing*, 16, 274-281.

TOOKEY, S., RENZI, C., WALLER, J., VON WAGNER, C. & WHITAKER, K. L. 2018. Using the candidacy framework to understand how doctor-patient interactions influence perceived eligibility to seek help for cancer alarm symptoms: a qualitative interview study. *BMC Health Services Research*, 18, 937.

TOWNSEND, P. 1979. *Poverty in the United Kingdom A Survey of Household Resources and Standards of Living*, Middlesex, Penguin Books.

TOWNSEND, P., PHILLIMORE, P. & BEATTIE, A. 1988. Health and deprivation. Inequality and the North. London: Croom Helm.

TROCHIM, W. M. K. 1989. Outcome pattern matching and program theory. *Evaluation and Program Planning*, 12, 355-366.

TUCA, A., GÓMEZ-MARTÍNEZ, M. & PRAT, A. 2018. Predictive model of complexity in early palliative care: a cohort of advanced cancer patients (PALCOM study). *Supportive Care in Cancer*, 26, 241-249.

VAISMORADI, M., TURUNEN, H. & BONDAS, T. 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15, 398-405.

VENKATAPURAM, S. 2011. *Health Justice: An Argument from the Capabilities Approach*, Oxford, Polity Press.

WALES, J., KURAHASHI, A. M. & HUSAIN, A. 2018. The interaction of socioeconomic status with place of death: a qualitative analysis of physician experiences. *BMC Palliative Care*, 17.

WALSH, B. & LAUDICELLA, M. 2017. Disparities in Cancer Care and Costs At the End of Life: Evidence from England's National Health Service. *Health Affairs (Millwood)*, 36, 1218-1226.

WALSH, D., BENDEL, N., JONES, R. & HANLON, P. 2010. It's not 'just deprivation': Why do equally deprived UK cities experience different health outcomes? *Public Health*, 124, 487-495.

WALSHE, C. 2006. *What Influences referrals within community palliative care services? A case study*. PhD, University of Manchester.

WALSHE, C. 2011. The evaluation of complex interventions in palliative care: An exploration of the potential of case study research strategies. *Palliative Medicine*, 25, 774-781.

WALSHE, C., CHEW-GRAHAM, C., TODD, C. & CARESS, A. 2008. What influences referrals within community palliative care services? A qualitative case study. *Social Science & Medicine*, 67, 137-146.

WALSHE, C., TODD, C., CARESS, A. & CHEW-GRAHAM, C. 2009. Patterns of Access to Community Palliative Care Services: A Literature Review. *Journal of Pain and Symptom Management*, 37, 884-912.

WALSHE, C. E., CARESS, A. L., CHEW-GRAHAM, C. & TODD, C. J. 2004. Case studies: A research strategy appropriate for palliative care? *Palliative Medicine*, 18, 677-684.

WALTON, E., AHMED, A., BURTON, C. & MATHERS, N. 2018. Influences of socioeconomic deprivation on GPs' decisions to refer patients to cardiology: a qualitative study. *British Journal of General Practice*, 68, e826-e834.

WHITEHEAD, M., BAMBRA, C., BARR, B., BOWLES, J., CAULFIELD, R., DORAN, T., HARRISON, D., LYNCH, A., MCINROY, N., PLEASANT, S. & WELDON, J. 2014. Due North. Report of the Inquiry on Health Equity for the North. Great Britain: Inquiry on Health Equity for the North.

WHITEHEAD, M. & DAHLGREN, G. 2006. Concepts and Principles for Tackling Social Inequities in Health: Levelling Up Part 1. Geneva: World Health Organisation.

WHO 2002. National Cancer Control Programmes. Policies and managerial guidelines. Second edition. Geneva: World Health Programme.

WILLIAMS, B. R. 2004. Dying Young, Dying Poor: A Sociological Examination of Existential Suffering Among Low-Socioeconomic Status Patients. *Journal of Palliative Medicine*, 7, 27-37.

WILLIAMS, L. A., GIDDINGS, L. S., BELLAMY, G. & GOTTFRIED, M. 2017. 'Because it's the wife who has to look after the man': A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life. *Palliative Medicine*, 31, 223-230.

WILSON, B. 2009. Can patient lifestyle influence the management of pain? *Journal of Clinical Nursing*, 18, 399-408.

WILSON, F., INGLETON, C., GOTTFRIED, M. & GARDINER, C. 2014. Autonomy and choice in palliative care: time for a new model? *Journal of Advanced Nursing*, 70, 1020-1029.

WITHAM, G., GALVANI, S. & PEACOCK, M. 2019. End of life care for people with alcohol and drug problems: Findings from a Rapid Evidence Assessment. *Health & Social Care in the Community*, 27, e637-e650.

WOOD, D. J., CLARK, D. & GATRELL, A. C. 2004. Equity of access to adult hospice inpatient care within north-west England. *Palliative Medicine*, 18, 543-549.

WOODS, S. 2007. *Death's dominion ethics at the end of life*, Open University Press.

WYNN, D. & WILLIAMS, C. 2012. Principles for Conducting Critical Realist Case Study Research in Information Systems. *MIS Quarterly*, 36, 787-810.

YIN, R. K. 2012. Case study methods. In: COOPER, H., CAMIC, P. M., LONG, D. L., PANTER, A. T., RINDSKOPF, D. & SHER, K. J. (eds.) *APA handbooks in psychology®. APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* American Psychological Association.

YIN, R. K. 2014. *Case study research : design and methods*, Thousand Oaks, Sage Publications.

YIN, R. K. 2018. *Case study research and applications : design and methods*, Thousand Oaks, Sage Publications.

YOUNG, R. & SLY, F. 2010. Portrait of the North West. *Regional Trends*, 43, 169-198.

ZIEGLER, L. E., CRAIG, C. L., WEST, R. M., CARDER, P., HURLOW, A., MILLARES-MARTIN, P., HALL, G. & BENNETT, M. I. 2018. Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. *BMJ Open*, 8, e018284.

# Appendices

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## Appendix A: Example search strategy

**Table A. 1: Medline (EBSCO) search strategy**

S13	S6 AND S9 AND S12
S12	S10 OR S11
S11	(MH "Health Care Quality, Access, and Evaluation") OR (MH "Health Services Accessibility") OR (MH "Referral and Consultation") OR (MH "Patient Acceptance of Health Care") OR (MH "Treatment Refusal") OR (MH "Referral and Consultation") OR (MH "Gatekeeping") OR (MH "Health Care Delivery")
S10	TX ( refer* OR experience* OR access OR Utilisation OR utilization OR barrier* OR facilitat* ) OR TX ( service* N5 (pattern* OR provision OR delivery OR supply OR distribution OR availability OR use OR uptake) ) OR TX ( perception* N5 (hospice OR palliative OR terminal OR death OR dying OR "end of life" OR end-of-life) ) OR TX ( awareness* N5 (hospice OR palliative OR terminal OR death OR dying OR "end of life" OR end-of-life) ) OR TX ( attitude* N5 (hospice OR palliative OR terminal OR death OR dying OR "end of life" OR end-of-life) ) OR TX ( accepta* N5 (hospice OR palliative OR terminal OR death OR dying OR "end of life" OR end-of-life) ) OR TX ( knowledge* N5 (hospice OR palliative OR "end of life" OR end-of-life) ) OR TX ( afford* N5 (hospice OR palliative OR "end of life" OR end-of-life) ) OR TX ( demand* N5 (hospice OR palliative OR "end of life" OR end-of-life) ) OR TX ( availability N5 (hospice OR palliative OR "end of life" OR end-of-life) ) OR TX ( ("decision making" OR decision-making) N6 (palliative OR hospice* OR "end of life" OR end-of-life) ) OR TX ( (Myth* adj5 (palliative or "end of life" or hospice OR end-of-life)) OR (Misconception* adj5 (palliative or "end of life" or hospice OR end-of-life)) )
S9	S7 OR S8
S8	(MH "Poverty") OR (MH "Social Class") OR (MH "Socioeconomic Factors")
S7	TI ( socioeconomic* N2 disparit* OR disadvantage* OR inequality* OR inequit* OR equit* OR depriv* ) OR AB ( socioeconomic* N2 disparit* OR disadvantage* OR inequality* OR inequit* OR equit* OR depriv* ) OR TI ( Social N2 disparit* OR disadvantage* OR inequality* OR inequit* OR equit* OR depriv* OR determinant* ) OR AB ( Social N2 disparit* OR disadvantage* OR inequality* OR inequit* OR equit* OR depriv* OR determinant* ) OR TI ( "medically uninsured" OR "social class" OR "social capital" OR poverty OR low-income OR discriminat* OR income ) OR AB ( "medically uninsured" OR "social class" OR "social capital" OR poverty OR low-income OR discriminat* OR income )
S6	S1 OR S1
S2	(MH "Hospice Care") OR (MH "Hospices") OR (MH "Terminal Care") OR (MH "Hospice and Palliative Care Nursing") OR (MH "Palliative Medicine") OR (MH "Attitude to Death")

S1	TI ( hospice* or palliat* or "end of life" or "end-of-life" or dying or (terminal* N6 ill*) or (terminal* N6 care*) ) OR AB ( hospice* or palliat* or "end of life" or "end-of-life" or dying or (terminal* N6 ill*) or (terminal* N6 care*) )
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## Appendix B: Study eligibility criteria

Table A. 2: Study eligibility criteria

	Inclusion criteria	Exclusion criteria
<b>Type of evidence</b>	Peer-reviewed journal articles (original data – e.g. population studies, qualitative data) Grey literature reports Commentary/opinion articles based on primary data findings	Systematic reviews Abstracts Opinion/commentary pieces not based on primary data findings
<b>Study population</b>	Adult (+18) patients Have an advanced progressive illness Described in socioeconomic terms <b>OR</b> The families of these patients Health and social care workers treating these patients Hospice organisations providing care to these patients	Patients under 18 Currently homeless Currently in prison
<b>Study topic</b>	Access to SPC, including:  Awareness of hospice or palliative care (HPC). Alternative terms: end-of-life care, terminal care Availability and quality of resources (patient: practical, social, family, financial, advocacy) (services: availability, capacity) Attitudes towards or perception of HPC Attitudes towards death, dying, or terminal illness Referral experiences/decisions/criteria Communication (patient: articulation, verbal activity) (clinician: prognosis, information sharing) Relationship between patients/families and HPC staff or referrers Stigma HPC values or culture Gatekeeping Demanding or help-seeking behaviours Resistance to/refusal of care Joined up or fragmented care Normalisation or downgrading of symptoms Utilisation or receipt of care	Place of death Advanced care planning Supportive care
<b>Study measures</b>	A measure of socioeconomic position should be explicitly mentioned in either the title or abstract of the study. Socioeconomic position is measured by:	Studies that only report Ethnicity Age

	<p>Area/postcode deprivation            Income (household/individual)            Education            Employment (prior illness)            Social Class            Social capital            Subjective measures (e.g. perception of socioeconomic position)  <u>OR</u>            Any other measure described as a measure of socioeconomic position/disadvantage/deprivation/poverty</p>	Gender
<b>Language</b>	English language	Language other than English
<b>Setting</b>	UK settings	Outside UK
<b>Timescale</b>	Published 1990 or later	Published before 1990

## Appendix C: Stage 1 of a narrative synthesis

**Table A. 3: Stage 1 of a narrative synthesis: Developing a theoretical understanding**

<b>Stage of access</b>	<b>Factors that shape access</b>	<b>Factors in the original model</b>	<b>Additional hospice-related factors</b>
Identification of candidacy	Acceptance of death Acceptance of terminal illness Awareness of death or dying Help-seeking behaviours Normalisation of symptoms Patient or family downgrading symptoms Lifetime experience of ill health	Services more likely to be used as a series of crises. Help-seeking likely to occur in response to specific events rather than planned. Symptoms may be “downgraded”. Lack of positive conceptualising of health. Normalisation of symptoms due to consistent experience of ill health in self and in community/family.	Differences in acceptance of death or awareness of death may affect whether someone sees themselves as a suitable candidate for hospice care. It may affect desires to make plans about an individual’s death, making end of life discussions more difficult.
Navigation	Knowledge or awareness of hospice Knowledge or awareness of services Available resources – practical, social, financial, mobile (e.g. transport)	Awareness of services on offer. Mobilising practical resources (e.g. time off work, financial support). Mobilising social resources (e.g. support at home, support for transport).	Differences in awareness of hospice services may lead to misunderstandings, and therefore rejection of referrals. Some people may have less access to advocates (social support) who support people to ask for help or to articulate needs. May be processes to overcome some resources problems but perception of these problems may be enough to deter someone from accepting hospice care.
Permeability of services	Perception of hospice/services Hospice culture Attitudes towards death or dying Service availability Type of services available Experiences of gatekeepers (e.g. referrers – GPs, nurses etc)	The way services are organised affects the ease with which people can access them (or how ‘permeable’ a service is). Some services require referrals, certain symptoms, a certain diagnosis, in order to access them. Less permeable services ‘demand a	Referral typically needed to access specialised hospice care. Diagnosis and symptoms are required for a referral to be generated. A hospice death or a ‘good’ death may not be culturally aligned with the preferences of everyone in society.

		<p>higher degree of cultural alignment between themselves and their users'. Comfort with organisational values of service and referrer important. Satisfaction following previous encounters may affect later experiences.</p>	
Appearances	<p>Articulating symptoms/ issues/ needs Verbal activity Demand for care or support Persistence</p>	<p>People make 'claims' for their right to access services. Patients required to formulate and articulate issue in a way that aligns with clinical assessment. Social distance between clinician and patients may make this harder.</p>	<p>Palliative care may differ slightly in that a patient will already be known to a clinician and unlikely to be 'presenting' for the first time with end of life symptoms.</p>
Adjudication	<p>Referral decisions Criteria for referrals Clinician knowledge of services Clinician engagement with services Clinician assumptions about patient's ability to benefit</p>	<p>Clinicians have to make judgement calls about who to refer and who to accept into a service. These decisions are strongly linked to relationships with other clinicians, local resources and capacity. Clinicians may ask how likely a patient is to benefit from an intervention (sometimes this may have social criteria).</p>	<p>Clinical judgements made on who is likely to benefit from hospice (e.g. symptoms, diagnosis). In disadvantaged areas, clinicians have less time to engage with services in local area and build their knowledge of local palliative care support available. Or they may look to offload work by increasing referrals.</p>
Offers and resistance	<p>Refusal of care Resistance to care Perception of hospice Family rejection of care</p>	<p>Patient (or family) may resist offers of referral. Resistance may be due to patient's identification of candidacy (see above) or perception of service etc.</p>	<p>Rejection may be due to differences in acceptance of terminal phase of illness, desire for curative care, attitude towards death and dying (see above).</p>
Local operating conditions	<p>Local resources Local capacity Availability of services Joined up care Fragmented care</p>	<p>Locally specific influences on interactions between patients and clinicians. Fragmented complex systems harder to</p>	<p>Always a limit to number of people who can receive care from hospice. In reduced circumstances, disadvantaged groups</p>

		<p>navigate for disadvantaged groups. Resource scarcity may prevent referrals (tied to adjudication).</p>	<p>more likely to miss out due to above reasons.</p>
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## Appendix D: Initial cross-case data matrix

**Table A. 4: Cross-case data matrix of initial findings.** *Green text = agreement between cases, red text = difference between cases.*

	Case 1	Case 2	Case 4
Outcome	<p>20% most deprived areas associated with marginally higher referrals than other areas once other variables accounted for but this was not statistically significant.</p> <p>Before accounting for other variables, more referrals in 20% most deprived areas.</p> <p>Patients referred initially by district nursing teams were less likely to be from a more deprived area than those referred by other referrers. No statistically significant difference between GP surgery referrals and hospital referrals.</p> <p>Patients who initially received day hospice services were more likely to be from a more deprived area than those referred to hospice at home or inpatient care.</p>	<p>20% most deprived areas associated with marginally higher referrals than other areas once other variables accounted for but this was not statistically significant.</p> <p>Before accounting for other variables, fewer referrals in 20% most deprived areas.</p> <p>Patients initially referred from GP surgeries were less likely to be from more deprived areas than those referred by hospital or out of hours care.</p> <p>There were a very low number of initial referrals from district nursing teams.</p> <p>There were no statistically significant differences in the initial service received between patients in different areas of deprivation</p>	<p>20% most deprived areas associated with substantially lower number of referrals, once other variables accounted for but this was not statistically significant.</p> <p>Before accounting for other variables, no difference in referrals.</p> <p>Patients initially referred from hospital were more likely to be from more deprived areas than those referred by district nurses or community nurse specialists.</p> <p>Very low number of referrals from GPs.</p> <p>Younger hospice patients were more likely to be from more deprived areas.</p> <p>No difference in the diagnosis of patients living in different areas of deprivation.</p>

	<p>Younger hospice patients were more likely to be from more deprived areas.</p> <p>Once adjusted for age and gender, hospice patients with a primary non-cancer diagnosis were more likely to be from more deprived areas.</p> <p>The gender of hospice patients did not appear associated with the area deprivation of where they were from.</p>	<p>Younger hospice patients were more likely to be from more deprived areas.</p> <p>Once adjusted for age and gender, hospice patients with a primary non-cancer diagnosis were more likely to be from more deprived areas.</p> <p>The gender of hospice patients did not appear associated with the area deprivation of where they were from.</p>	<p>No evidence of association between gender and area deprivation.</p>
Summary of case	<p>Challenges professionals faced in consultations with some patients and families experiencing socioeconomic disadvantage in this case could have feasibly contributed to referrals from more deprived areas. Several participants felt that some disadvantaged families had difficulties taking ownership of the situation as a patient's illness worsened and their needs increased. They also described high levels of psychological need amongst patients and families in the more deprived areas, due in part to the prevalence of pre-existing mental health problems. Several participants linked this burden to the absence of accessible high-level psychological care for severe mental illness in the more deprived areas of this case. These challenges meant that consultations with some patients and families in</p>	<p>The evidence from participants in this case contributed to two overarching observations about hospice care for people living in the socially deprived areas in this region. The first is about the about the main initial contact with hospice care being triggered from a hospital-based referrer, or one based in out of hours care, rather than from someone based in primary care. This enabled the hospice to pick up a proportion of patients from more socially deprived areas who connected with healthcare services when experiencing a crisis. The second overarching observation, and perhaps the strongest one, was about the challenges of caring for patients who might resist or 'not engage' with care services in a way that fits hospice notions of appropriate end-of-life care. It was not clear how this might influence referrals. Although</p>	<p>A combination of extensive and close-knit family networks and a culture of resistance to input from services until a crisis occurs contributed to lower referrals from the more deprived areas in this case. Referrals were predominantly made to the home nursing team to help support the family as main caregivers. Patients in more chaotic environments due to substance dependencies or mental health issues were perceived problematic for hospice home nursing due to safeguarding issues for lone workers. The scope of hospice home nursing tended to be towards the end of life and primarily for family support. The challenges of fitting 'untypical' dying, including those living in more chaotic environments and dying from non-cancer conditions,</p>

	<p>socially deprived areas towards the end of life tended to be more time intensive, requiring multiple and longer visits. The interaction between this and overstretched primary care resources in the more deprived areas created an environment in these areas that would feasibly drive more referrals to the hospice.</p>	<p>not engaging with services may contribute to lower referrals, there were many examples of patients referred to hospice but who distanced themselves from ongoing input. This created a professional and sometimes emotional dilemma for hospice staff who struggled with the tension between the disadvantaged circumstances of patients' lives and the ideals of good end-of-life care.</p>	<p>into a family-orientated end of life model of hospice care may have disadvantaged patients in socially deprived areas in this case. This was particularly the case for patients with conditions associated with socioeconomic deprivation and who were accessing urgent care.</p>
Factors	<p>Consultations with patients and families who were socioeconomically disadvantaged towards the end of life tended to be more time intensive, requiring multiple and longer visits.</p> <p>Lack of continuity and not enough time to spend with primary care patients in deprived areas</p> <p>Participants reported families and patients having difficulties taking ownership</p> <p>Expression of psychological distress at the end of life was noticeably different in deprived areas</p>	<p>Not being able to either obtain or attend GP appointments feasibly creates an environment not conducive to referrals</p> <p>The lives of patients in deprived areas leads to them keeping a distance from healthcare services.</p> <p>However, the emphasis was on barriers to engaging with end-of-life care after referral rather than the absence of referrals</p> <p>Expectations are lower in socially deprived areas with participants noting people appeared grateful and surprised when care was put in.</p> <p>Patients in socially deprived areas reach out to healthcare services when a crisis occurs or care needs become the priority</p> <p>Hospice staff wrestle between paternalism and patient-led decision-making in areas where people live in disadvantaged circumstances.</p>	<p>Family support in more deprived areas led to less dependency on hospice care</p> <p>There was also a culture of resisting input from healthcare services in more deprived areas, driving by different reasons</p> <p>The hospice was unable to provide care to some patients in more chaotic environments because of safeguarding issues</p> <p>Non-cancer patients accessing urgent care may find it particularly hard to receive hospice referral</p>

Context	<p>Lack of high-level psychological care (inequality of provision within hospice catchment area)</p> <p>No specific hospice strategy to reach vulnerable populations</p> <p>Respiratory consultant proactively created respiratory session</p> <p>CNS team outside the hospice (at time of case)</p>	<p>Integration into hospital site</p> <p>Environment in hospital and attitude of staff conducive to close patient contact and ongoing education of staff</p> <p>Hospice integrated into out of hours care</p> <p>Hospice top-down strategy of reaching out to vulnerable groups</p> <p>Hospice top-down and bottom-up strategy of reaching patients with non-cancer conditions</p> <p>Perceived shift increased drug use in population</p> <p>Perceived large patient population without a home/living in multiple occupancy housing</p> <p>CNS team internal to hospice</p>	<p>Closely integrated with CNS</p> <p>Much of hospice work was done in direct contact with district nurses and community nurse specialists. Referrals tended to come through those channels, as well as the hospital</p> <p>Small scope - specific model of care designed for 12 months but last few weeks of life and largely about family support and day/night respite</p> <p>No hospice beds (few inpatient beds), no day hospice – restriction from geography.</p> <p>Considerable geographical isolation and spread. Isolation may contribute to extensive family networks.</p> <p>Lack of specialist services.</p> <p>Historical context: Poor access to oncology. Social historical context: Mining towns and villages</p> <p>Ease of communication, perhaps due to few services or resources.</p> <p>Barriers to direct referrals to the hospice from acute, out of hours etc</p>
Theoretical links	<p>HCP adjudicate based on time and nature of interactions dictated by continuity – a resource and a characteristic constrained or</p>	<p>Resistance to care input also ties to lower likelihood of identifying self as having a need for hospice care (although this is an assumption – it may be that people do identify a need</p>	<p>Also, considerable resistance to care, identification of candidacy dependent on families as much patients.</p>

	<p>expanded by local operating conditions.</p> <p>Need for care drives organisation of services (e.g. respiratory driving day care) but also services drive needs (i.e. once that service exists the hospice becomes more accessible because it fits their needs)</p>	<p>but still resist the care offered to them). Resistance was evident post referral. Patients might be wrestling with conflicting emotions about accepting someone, identifying their need, and also not wanting the care provided. Don't want to over interpret without patient input.</p> <p>SEDP reach out at times of crisis – fits into permeability concept. Seek care that will respond immediately because of crisis situation.</p> <p>Pressure on GPs, difficulties accessing, perhaps generating hospital admissions. Indication of the importance of local operating conditions.</p>	<p>Strongest (?) sense of local operating conditions creating an environment in which decisions are made and therefore influencing those decisions. E.g. lack of access to carers generating need for hospice input coupled with isolated area having family networks, creating environment where hospice input needed less.</p> <p>Emphasis is really on referrers to initially identify need for referral, not on patients.</p>
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## Appendix E: Hospice referral rates

Information about the analytical methods are provided in the methods chapter (section 5.7.2).

### Area characteristics

Table A.5 shows the area characteristics in each case. The equal distribution of areas in the case across deprivation quintiles (where 1 is the most deprived, and 5 is the least deprived) is to be expected, reflecting the process of ranking areas in relation to one another locally before categorising them into quintiles. The cases were similar in their distribution of gender, ethnicity, and age, with a greater percentage of the populations white and aged below 65, and a nearly equal distribution of men and women. However, Case 3 had more rural areas, Case 2 more urban, and Case 1 there was an even split between rural and urban areas.

**Table A. 5: Area characteristics in Cases 1-3**

Variable		% C1 C2 C3		
		C1	C2	C3
Deprivation quintile <sup>1</sup>	Most deprived -1	20	20	21
	2	20	20	20
	3	20	20	20
	4	20	20	20
	Least deprived - 5	20	20	21
Geography	Rural	50	9	61
	Urban	50	91	39
Gender <sup>2</sup>	Female	51	51	50
	Male	49	49	50
Ethnicity <sup>2</sup>	White	97	97	99
	Other than white	3	3	1
Age <sup>2</sup>	65 and over	24	24	22
	Under 65	76	76	78

<sup>1</sup> Calculated from regional deprivation ranks

<sup>2</sup> Mean value across all LSOAs in Case 3

### Referrals distribution

In each case, hospice referrals followed a Poisson distribution overall and for each of the five deprivation quintiles (1 – most deprived) as shown in the density in Figure [A.1]. Like histograms, density plots show the distribution of data but treat the data as continuous. This provides a more accurate picture of distribution than when data are ‘binned’ into separate groups along the x-axis, as is done in a histogram.

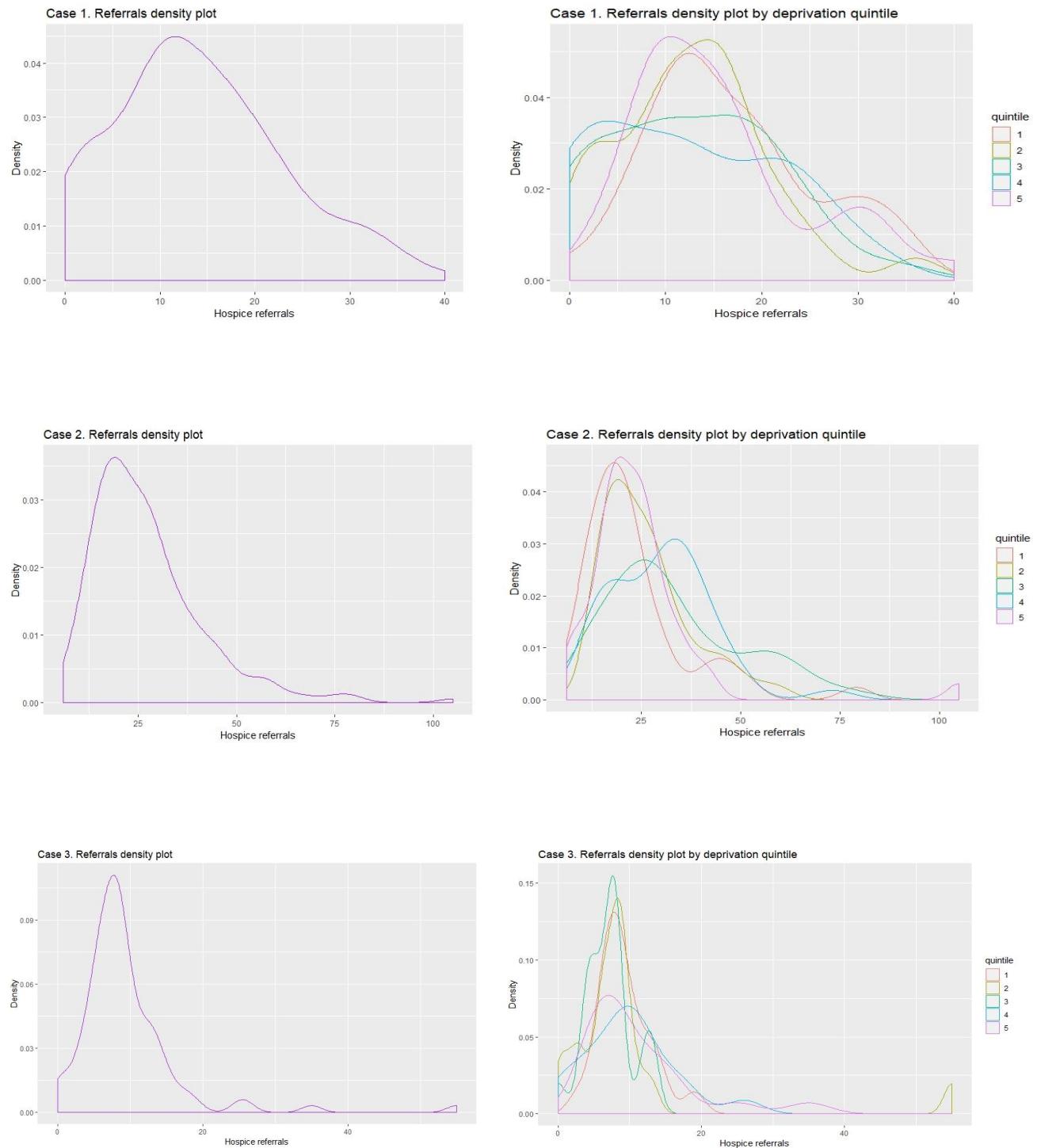
#### **Association between referrals and other variables**

Univariate analyses (Poisson regression models) of area characteristics and hospice referral, are run separate for each of the three cases. Table A.6 explores the relationship between different area characteristics and hospice referrals in each case. The Incidence Rate Ratios (IRR) indicates the ratio change in hospice referral rate when there is a one-unit change in the corresponding variable for that row. The IRR for deprivation in Case 1 (C1) indicates that as deprivation worsens, hospice referral rates increase by a ratio of 1.49, in a univariate analysis. This is when comparing the 20% most deprived areas to all other areas in that case. An IRR greater than 1 indicates that referrals increase with a corresponding one unit change in that variable; an IRR less than 1 indicates that referrals decrease.

Table A. 6: Univariate analysis of hospice referral rates by area characteristics

Variable	IRR		
	C1	C2	C3
Deprivation (20% most deprived)	1.49*	0.94	0.94
Geography (Urban)	1.24*	1.23*	1.15*
Age (% over 65)	1.01*	1.03*	1.03*
Gender (% female)	1.10*	1.02*	1.01
Ethnicity (% white)	1.04	1.00	0.99
Mortality rate (per 1k)	1.03*	1.04*	1.04*
Distance (km)	0.97*	0.99	0.99*

\*p<0.05



**Figure A. 1: Density plots of all hospice referrals and by deprivation in cases 1-3**

### Testing for overdispersion

All variables were entered into a multivariate fixed effect Poisson regression model, using stepwise regression to choose the best fitting model, with a separate model for each case. A goodness of fit test was performed on the fixed effects model. This tests whether the deviance (different between expected and observed values) differs statistically significantly from the deviance of the model were the expected values to match the observed values. A statistically significant result ( $p \leq 0.05$ ) suggests evidence of a difference in deviance, and thus indicates overdispersion. Table A.7 presents the result of this test for cases 1-3, indicating overdispersion.

**Table A. 7: Goodness of fit test**

	Residual deviance	Degrees of freedom	P value
C1	618.86	151	0.00
C2	453.76	199	0.00
C3	257.31	88	0.00

#### **Fitting the random effect model**

The data were subsequently fitted in a random effects model, with the Lower Layer Super Output Area (LSOA) included as a random effect. To allow the model to converge, some of the variables in each case analysis were rescaled to between 0 and 1 by dividing each rate by the range. The coefficient was rescaled (by dividing by same amount) before generating incidence rate ratios. The output of the random effect analyses for each case are included in Chapter 6. Table A.8 reports results from a comparison of models using anova, indicating that the random effects model is a statistically significant better fit than the fixed effects model in each case.

Table A. 8: Model comparison using Anova

		Df	AIC	BIC	logLik	deviance	Chisq	Chi Df	P value
C1	Fixed effects	6	1277	1296	-632.72	1265.44	-	-	-
	Random effects	7	1091	1113	-538.66	1077.33	188.11	1	0.00
C2	Fixed effects	7	1504	1528	-745.22	1490.43	-	-	-
	Random effects	8	1399	1426	-691.57	1383.13	107.3	1	0.00
C3	Fixed effects	5	639.33	651.94	-314.67	629.33	-	-	-
	Random effects	6	557.81	572.94	-272.91	545.81	83.52	1	0.00

## Appendix F: Patient characteristics

### Case 1

Table A.9 presents the distribution of patients across different characteristics. A higher proportion of patients fell in the most deprived regional quintile, received hospice at home care, were referred by a GP surgery, had a primary cancer diagnosis, and were female. Patient ages ranged from 19 to 100, with a mean of 75 (Table A.10).

**Table A. 9: Patient characteristics (Case 1)**

Characteristics	Category	N	%
Deprivation	Most deprived – 1	540	24.46
	2	395	17.89
	3	393	17.8
	4	382	17.3
	Least deprived - 5	498	22.55
Service	Day hospice	419	18.98
	Hospice at home	760	34.42
	Inpatient hospice	563	25.5
	Missing	466	21.11
Referrer	GP surgery	509	23.05
	Clinical nurse specialist	234	10.6
	District nurse	293	13.27
	Hospice (internal)	466	21.11
	Hospital	434	19.66
	Other	212	9.6
	Missing	60	2.72
Diagnosis	Cancer	1393	63.09
	Non-cancer	662	29.98
	Missing	153	6.93
Gender	Female	1134	51.36
	Male	1074	48.64

**Table A. 10: Patient age (Case 1)**

	Min	Max	Mean
Age	19	100	75

### Case 2

Table A.11 presents the distribution of patients across different characteristics in Case 2. A higher proportion of patients fell in the middle regional deprivation quintile, were referred to hospital-based hospice care, were referred from hospital settings, had a primary cancer diagnosis, and were female. Patient ages ranged from 17 to 107, with a mean of 77 (Table A.12).

**Table A. 11: Patient characteristics (Case 2)**

Characteristics	Category	N	%
Deprivation	Most deprived – 1	975	17.33
	2	1076	19.13
	3	1357	24.12
	4	1224	21.76
	Least deprived - 5	994	17.67
Service	Community	1604	28.51
	Day	252	4.48
	Hospice at Home	1167	20.74
	Hospital	2508	44.58
	Inpatient	52	0.92
	Outpatient consultant	43	0.76
Referrer	Community	80	1.42
	GP surgery	748	13.3
	Hospital	3491	62.05
	Hospice (internal)	143	2.54
	Out of hours	1158	20.58
	Other	6	0.11
Diagnosis	Cancer	2829	50.28
	Noncancer	1757	31.23
	Missing	1040	18.49
Gender	Female	2965	52.7
	Male	2661	47.3

**Table A. 12: Patient age (Case 2)**

	Min	Max	Mean
Age	17	107	77

### **Case 3**

Table A.13 presents the distribution of patients across different characteristics in Case 3. A higher proportion of patients fell in the middle regional deprivation quintile, were referred by a clinical nurse

specialist, had a primary cancer diagnosis, and were female. Patient ages ranged from 21 to 107, with a mean of 78 (Table A.14).

**Table A. 13: Patient characteristics (Case 3)**

Characteristics	Category	N	%
Deprivation	Most deprived – 1	176	20.35
	2	171	19.77
	3	128	14.8
	4	179	20.69
	Least deprived - 5	211	24.39
Service	Hospice at home	865	100
Referrer	Clinical nurse specialist	266	30.75
	District nursing	141	16.3
	Hospital	157	18.15
	Informal	39	4.51
	Hospice (internal)	3	0.35
	Other	63	7.28
	Other HCP	195	22.54
Diagnosis	Missing	1	0.12
	Cancer	602	69.6
Gender	Noncancer	263	30.4
	Female	443	51.21
	Male	422	48.79

**Table A. 14: Patient age (Case 3)**

	Min	Max	Mean
Age	21	107	78

## Appendix G: Late referrals

The third analysis conducted in each case concerned the relationship between the area of deprivation where a patient lived and how late they were referred to hospice. Late referral was determined by the length of time patients received hospice care (days between initial referral and death), with three different thresholds used:

- 1) Late referrals defined as patients referred  $\leq$  30 days before death (Allsop et al, 2019)

- 2) Late referrals defined as patients referred  $\leq$  14 days before death, to capture any differences in very late referrals by area social deprivation
- 3) Late referrals defined by the median length of time receiving hospice care for all patients in that case (for Case 1,  $\leq$ 24 days; for Case 2,  $\leq$ 13 days; for Case 3  $\leq$ 8 days)

Table A.15 reports the number of patients in each case for whom a date of death was recorded, and whose length of time they received hospice care was 0 or above.

**Table A. 15: Patient (n) included in late referrals analysis**

	C1	C2	C3
Number of patients	1330	3948	763

Because of extreme values in this data, the median is the most appropriate average for comparing length of time between different groups. Table A.16 shows the average length of time between first referral and death for all patients across the three cases. Table A.17 breaks this down by different patient characteristics. Whereas in Case 1 the median length of time receiving hospice care decreases as patient live in increasingly less deprived areas (with the exception of quintile 4), there is no discernible pattern across area deprivation in Cases 2 and 3 (Table A.17). In all cases, the median length of time receiving hospice care is greater for patients with a primary cancer diagnosis and patients with a non-cancer diagnosis.

Table A. 16: Length of time (days) patients received hospice care<sup>1</sup>

		Min	25%	Median	Mean	75%	Max
Length of time (days)	<b>C1</b>	0	6	24	73	75	1101
	<b>C2</b>	0	5	13	62	58	1143
	<b>C3</b>	0	2	8	31	26	734

<sup>1</sup> C1=Case 1; C2= Case 2; C3= Case 3

Table A. 17 Length of time (days) patient received hospice care by patient characteristics<sup>1</sup>

Characteristic	Category	Mean			Median			25%			75%		
		C1	C2	C3	C1	C2	C3	C1	C2	C3	C1	C2	C3
Deprivation quintile	1 – most deprived	83	61	32	29	13	7	6	5	2	85	61	23
	2	81	60	27	28	12	7	7	5	2	98	52	30
	3	66	60	21	22	12	10	5	5	3	69	59	26
	4	64	60	30	25	13	7	7	5	3	67	56	20
	5 – least deprived	69	68	42	19	14	8	5	5	3	70	61	41
Age group	0-40	41	122	39	15	39	48	3	13	3	41	205	62
	41-60	87	110	27	27	40	11	8	10	4	93	132	23
	61-80	76	74	30	26	21	9	7	5	3	83	78	30
	81+	65	40	33	20	8	7	5	4	2	69	27	23
Gender	Female	72	60	32	25	11	8	6	4	2	75	46	24
	Male	73	64	31	23	15	8	6	5	3	74	68	30
Diagnosis	Cancer	72	90	33	26	35	11	7	12	3	77	105	31
	Noncancer	77	43	28	15	7	4	4	4	2	73	19	12

<sup>1</sup>C1=Case 1; C2=Case 2; C3=Case 3

Late referral was computed from length of time, where a time between referral and death (length of time)  $\leq 14$  days was defined as very late. Three separate binomial logistic regressions were performed, one for each case, with late referral (yes/no) as outcome and deprivation. Age and diagnosis were included as additional explanatory variables (based on statistically significant results in univariate analyses). Deprivation was not significantly associated with how late a patient was referred in any of the cases (Table A.18). This remained the same when late referrals were classed as  $\leq 30$  days,  $\leq 14$  days or by the median length of time between referral and death in each case. Having a non-cancer diagnosis was statistically significantly associated with late referral in each case, with the odds of someone with non-cancer being referred later than 14 days increasing by a ratio of 1.44 in Case 1, 4.98 in Case 2, and 2.22 in Case 3.

**Table A. 18: Odds ratios of late referrals ( $\leq 14$  days) by characteristics**

Characteristics	Odds Ratio		
	C1	C2	C3
Dep quintile 2	0.98	1.14	0.79
Dep quintile 3	1.11	0.97	0.78
Dep quintile 4	0.96	0.96	1.08
Dep quintile 5	1.19	0.85	0.81
Age	1.01	1.03*	1.00
Diagnosis (non-cancer)	1.44*	4.98*	2.22*

\*p< 0.05

## Appendix H: National and regional area deprivation

Each small area (LSOA) in each case is assigned an area deprivation rank (in the publicly available Index of Multiple Deprivation), positioning that area in relation to all other areas in England. These ranks can be turned into deprivation quintiles, with areas falling into different quintiles depending on the rank. Table A.19 reports the distribution of areas by national deprivation quintile within each case. The percentage columns indicate each case's catchment area has a different deprivation distribution (based on national rankings); Case 1 is skewed towards the least deprived quintiles, whereas Cases 2 and 3 are skewed towards the most deprived quintiles.

**Table A. 19: Distribution of national deprivation quintiles in Cases 1-3**

	Case 1		Case 2		Case 3	
	N	%	N	%	N	%
Quintile 1 (most deprived 20%)	21	13	61	30	23	25
Quintile 2	20	13	43	21	26	28
Quintile 3	34	22	45	22	21	23
Quintile 4	55	35	35	17	11	12
Quintile 5 (least deprived 20%)	27	17	22	11	11	12

Regional deprivation quintiles were calculated by comparing areas within the catchment area relevant to each case. The national deprivation ranks assigned to each small area (LSOA) were re-ranked in relation to others within the case. These regional deprivation ranks were transformed into regional deprivation quintiles. This resulted in deprivation being evenly distributed across these catchment areas (Table A.20). These were the measure of deprivation quintiles used in Analyses 1 (hospice referral rates) and 3 (late referrals); regional deprivation ranks were used in Analysis 2 (patient characteristics).

**Table A. 20: Distribution of regional deprivation quintiles in Cases 1-3**

	Case 1		Case 2		Case 3	
	N	%	N	%	N	%

Most deprived - 1	3 2	2 0	4 2	2 0	1 9	2 0
2	3 1	2 0	4 1	2 0	1 8	2 0
3	3 1	2 0	4 1	2 0	1 8	2 0
4	3 1	2 0	4 1	2 0	1 8	2 0
Least deprived -5	3 2	2 0	4 1	2 0	1 9	2 0

## Appendix I: Missing data

### *Case 1*

Click [here](#) to return to where Tables A.21-25 are referenced in the main thesis in Chapter 6.

**Table A. 21: Missing data by patient and provider characteristics (Case 1)**

	Category	N	%
Service	Day Hospice	419	19
	Hospice at Home	760	34
	Inpatient	563	25
	<b>Missing</b>	<b>466</b>	<b>21</b>
Referrer	Clinical nurse specialist	234	11
	District Nurse	293	13
	GP Surgery	509	23
	Hospice (internal)	466	21
	Hospital	434	20
	Other	212	10
	<b>Missing</b>	<b>60</b>	<b>3</b>
Diagnosis	Cancer	1393	63
	Non-cancer	662	30
	<b>Missing</b>	<b>153</b>	<b>7</b>

**Table A. 22: Distribution of missing data by regional deprivation quintile (Case 1)**

	Service		Referrer		Diagnosis	
	N	%	N	%	N	%
Most deprived - 1	125	27	11	18	38	25
2	93	20	19	32	25	16
3	72	15	12	20	27	18

4	85	18	7	12	34	22
Least deprived -5	91	20	11	18	29	19

*Case 2*

**Table A. 23: Missing data by patient and provider characteristics (Case 2)**

	Category	N	%
Diagnosis	Cancer	2829	50
	Non-cancer	1757	31
	Missing	1040	18

**Table A. 24: Distribution of missing data by regional deprivation quintile (Case 2)**

	Diagnosis	
	N	%
Most deprived - 1	177	17
2	195	19
3	256	25
4	229	22
Least deprived -5	183	18

*Case 3*

**Table A. 25: Missing data by patient and provider characteristics (Case 3)**

	Category	N	%
Referrer	Clinical Nurse Specialists	266	31
	District Nurse	141	16
	Hospital	157	18
	Informal	39	5
	Hospice (internal)	3	0.3
	Other (non-HCP) <sup>1</sup>	63	7
	Other HCP <sup>1</sup>	195	23
	Missing <sup>2</sup>	1	0.1

<sup>1</sup> HCP=Healthcare Professional  
<sup>2</sup> One missing data point was in deprivation quintile 4