The drive to discharge older people with frailty at the end of life from community hospital.

A constructivist grounded theory study.

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ABSTRACT

There has been an increasing acknowledgement in recent years of the importance of recognising frailty as a condition that leaves older people vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a minor infection or a change in medication or environment. Older people with frailty are those who are at highest risk of adverse outcomes such as falls, disability, admission to hospital, and the need for long-term care. The approach to managing frailty is often with an emphasis on staying well, even though, due to an increase in conditions such as dementia, heart disease, stroke and arthritis, Seymour (2017) suggests, 'end-of-life care' is 'care of older people'. Meanwhile, discharge from hospital continues to be contentious, with overstretched acute hospitals juxtaposed with community services that struggle to keep up with the demand of those being discharged. Studies that look at the combination of frailty, end of life and hospital discharge are limited. Furthermore, previous studies looking at these areas focus on perceptions of health professionals *or* patients and informal carers, but not on stakeholders as a whole.

This qualitative study explored the experiences of stakeholders involved in the discharge from hospital of an older person living with frailty who is nearing the end of life. This included the patient, their informal carer(s), community hospital staff, community health professionals and care home managers. A constructivist grounded theory methodology was used, and semi-structured interviews were conducted with 55 participants. The interview data were analysed and interpreted using the constant comparative method and situational analysis.

The study findings provided valuable insight into the experience of older people living with frailty approaching the end of life, their informal carers and health professionals involved in the discharge from community hospital. The study added to the knowledge of the discharge process for all stakeholders. The core category of 'the drive to discharge conveyor belt' was produced from the data analysis alongside four dynamic, interrelated conceptual categories and the subcategories within these. These conceptual categories were: 'resource limitations', 'mismatch in expectations', 'choice and control' and 'carer burden'. The study captured how the discharge conveyor belt is caused by and causes resource limitation, mismatch in expectations between health professionals, patients and carers and how concepts of choice and control influence decision making. These concepts combine to increase the carer burden. The carer was found to be 'intrinsic' to the discharge and

facilitating the older person living in their place of choice. Intersectionality was used to interrogate how the drive to discharge intersects with older people and their informal carers to create inequitable outcomes, and to generate recommendations.

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OVERVIEW OF THE CHAPTERS

Chapter 1: The introductory chapter provides an outline of the researcher's role and interest in the research area. This is followed by a summary of the background to the study. The rationale for the study, the study aims and the research questions are presented.

Chapter 2: The literature review provides an overview of the current knowledge and empirical studies relating to frailty, end of life and discharge from hospital. A policy summary and definitions are also included.

Chapter 3: This chapter provides an overview of constructivist grounded theory and the rationale for its choice as a methodology for the study. The research methods are outlined and the ethical considerations are discussed.

Chapter 4: The chapter presents an analysis of the findings. The core category of 'the discharge conveyor belt' and the four interrelated categories of 'resource limitations', 'mismatch in expectations', 'choice and control' and 'carer burden' are discussed. The substantive theory, which was produced from the integration of the categories, is presented.

Chapter 5: Developing the findings, this chapter explores the underlying mechanisms that explain how and why the drive to discharge exists and the impact this has both on older people living with frailty and on their carers. Intersectionality is used to interrogate the outcome of the drive to discharge/older person/carer intersection.

Chapter 6: The final chapter reviews the research questions and addresses study limitations. It concludes by discussing the implications for policy and practice and makes recommendations for further research.

Chapter 1: Introduction

1.1: Introduction

This introductory chapter outlines the background and rationale for this study. An explanation of my interest in the research area is articulated. A summary of the background to the study is presented, which contextualises the experience of older people living with frailty who are considered to be at the end of life and are being discharged from community hospitals. Other stakeholders are also included, such as the older person's informal carer(s) and health professionals in the community hospital and community services. This is followed by the aims of the study and presentation of the research questions.

1.2: Research rationale: a personal reflection

Whilst working as an Occupational Therapist I worked in the community, in hospital and hospice settings in the same locality. I noticed different attitudes and ways of working regarding end of life issues across the settings. This became more apparent whilst providing training on end of life conversations. What also stood out was the passion that NHS staff have for providing excellent care at the end of life and giving the patient as much choice as possible in place of death. It occurred to me that with such dedicated staff, who are committed to excellent end of life care, why do the issues highlighted in the literature persist? The disparity I observed in working practices and understanding of procedures, also made me wonder how this affects the patient and their family. I wondered what impact that had on the individuals and on the discharge process.

As an occupational therapist I am guided by patient-centred philosophy and models of practice. The professional body for occupational therapists in the UK, the Royal College of Occupational Therapists (RCOT), sets the benchmark for occupational therapy practice in the UK Code of Conduct by stating that: 'The College of Occupational Therapists is committed to client-centred practice and the involvement of the service user as a partner in all stages of the therapeutic process' (RCOT, 2015, p.v). In addition, the Code requires 'a continuing duty to respect and uphold the autonomy of service users, encouraging and enabling choice and partnership-working in the occupational therapy process' (RCOT, 2015, p.9). This set of principles led me to interview stakeholders in the discharge process in order to capture a snapshot of the current situation, constructed with the participant's voice at the fore and grounded in the data. I was keen to include stakeholders because the literature regarding

discharge at the end of life often fails to include a variety of stakeholders, instead leaning towards the views of doctors and nurses *or* patients and carers.

1.3: Discharge from hospital at the end of life and frailty

In 2008 the first national strategy for end of life care in England provided the health and social care system with three key insights: that people did not die in their place of choice; that we needed to prepare for larger numbers of dying people and that not everybody received high-quality care. 'Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not' (DoH, 2008). Other nation-specific strategies and reports have followed that encompass all ages, all four nations and all conditions (NHS Scotland, 2008; NHS Wales, 2013; Department of Health, Social Services and Public Safety, 2010). New care processes have been developed, new indicators of quality have been set, new systems for scrutiny devised, and new systems for funding are under development (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* (NPELCP, 2015) calls for 'a relentless focus on improving outcomes, including people's experience and quality of care, wherever the setting'. The framework highlights that the variation in quality of care at the end of life has become a point of national debate and that while death may not be a failure, poor care is. Between 2004 and 2008, 78% of people had at least one hospital admission in last year of their life (National end of life intelligence network, 2012). Therefore, part of the experience for many at the end of life is the discharge from hospital back to the community.

One area of inequitable care highlighted in the literature is older people who live with frailty who 'dwindle' at end of life, rather than follow a predictable trajectory, as with conditions such as cancer (Murray et al, 2005). Frailty is mentioned in the *End of Life Care Strategy* (DoH, 2008) regarding difficulty in assessing when end of life care should begin. Frailty is a 'distinctive health state related to ageing, characterised by impaired homeostasis and decreased physiological reserve across multiple body systems, and resulting in increased vulnerability to adverse outcomes from apparently minor stressor events' (Keeble et al, 2019b). Discharge from hospital is associated with increased two-year mortality for older people living with frailty. Keeble et al (2019b) found that older people living with frailty are at 'high risk of poor outcomes after hospital discharge and … that current services do not adequately meet their needs' (p.558). Hospital admissions in this group are commonly caused by 'frailty crises', and despite the increasing range of community-based services

geared towards admission avoidance, there has been a relentless rise in acute hospital admissions in this group. This creates significant pressures on hospital services, which are structured to promote early discharge, and with the assumption that longer-term problems will be addressed in the community later (Keeble et al, 2019b). The push to discharge is supported by a policy emphasis on dying at home, which does not take into account the relationality of dying, particularly for older people who become increasingly reliant on formal and informal care. Gott et al (2017a) found that dying at home was not a priority for older people, which is at odds with the policy priority. There is a complexity in the discharge of an older person living with frailty that gets overlooked in the push to discharge older people who are perceived as 'bed blocking' and draining acute hospital resources. Furthermore, the biomedical emphasis on managing the bodily decline inherent in frailty overlooks the end of life aspects of frailty.

With up to an estimated 12% of total health costs spent on care for people in their last year of life and the need for palliative care projected to increase by 42% by 2040, there is a need for appropriate care, in and out of hospital, 'to ensure every person approaching the end of their life, and their family and carers, has access to appropriate care, treatment and support' (End of life care coalition, 2017, para. 8). Therefore, this is an important area in which to improve experiences and outcomes for stakeholders. Previous studies into end of life issues or palliative care tend to look at patient and family or health professional perspectives separately. A literature search found few studies that take into account all the stakeholders' perspectives at the end of life, even though integrated care is a key area of interest in policy for its ability to improve experiences and save money through efficiency. A further literature search found scant evidence regarding frailty, end of life and hospital discharge. Research into the discharge from hospital of older people living with frailty can increase the evidence base in order to direct investment and planning, which in turn would reduce rising emergency admission and delayed discharges. This will benefit not only individuals but the health and social care system as a whole.

1.4: Aim of the research study

The purpose of this study was to explore the perceptions and experiences of stakeholders involved in the discharge from the hospital to the community of an older person living with frailty approaching the end of life. The research questions were:

1. How is discharge perceived and understood by stakeholders?

2. How is discharge experienced by stakeholders?

3. What structures and processes are in place to facilitate discharge?

In the study I have sometimes used the term ‘patient’ to describe the older person living with frailty who is being discharged from hospital. The term ‘carer’ or ‘informal carer’ refers to any family members, friends or neighbours who provided unpaid care to the older person living with frailty. Although the medical orientation of the use of these terms may be criticised, it was chosen as this is how the participants were referred to in the hospital and community settings, and alternatives such as ‘service user’ and ‘client’ are unsatisfactory and carry their own connotations. The term ‘stakeholder’ is applied to participants who were directly involved in the discharge process.

1.5: Summary

This chapter has provided an overview of the background and rationale for the study. The purpose of the study has been outlined and the research questions presented. The literature review undertaken to identify the current state of scientific knowledge relating to older people living with frailty and discharge from hospital at the end of life is presented in the next chapter, together with a policy analysis.

Chapter 2: Policy Analysis and Literature Review

2.1: Introduction

The aim of the chapter is to put the study into context historically, politically and with regard to current research. After an overview of definitions used within the thesis, the first section of this chapter will present a policy analysis of end of life care. The second section of the chapter comprises literature reviews of hospital discharge at end of life to explore how it has been studied to date.

2.2: Definitions

The terms 'end of life' and 'palliative' are frequently used interchangeably in the UK and there are different definitions used worldwide. As Middleton-Green et al (2017) assert, 'definitions matter'. Clarity is required at academic and policy level, with definitions providing an agreed understanding with which services can then be organised and evaluated. The terms used in this study are presented in Figure 1. The World Health Organisation (WHO, 1998) provides a definition of palliative care but not of end of life care. However, the *End of Life Care Strategy* (DoH, 2008) indicates that end of life is the last 6–12 months of life. Neuberger (2013) in the review of the Liverpool Care Pathway adds to the definition that someone may be 'at risk of dying in 6–12 months but may live for years' (p.14). I feel these are combined eloquently in the New Zealand definition (Figure 1). Middleton-Green et al (2017) add 'terminal care' to define the 'last hours, days or possibly weeks of life' (p.28). They report that the term 'actively dying' has started to appear in recent literature, which also describes the terminal phase.

End of life: That period of time prior to death, but the duration can never be precisely defined in advance… The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. The major transition to the end of life period is in changing the focus on the person from curative and restorative care, which aims to extend the quantity of life, to palliative care which aims to improve the quality of life. (Ministry of Health (New Zealand), 2015, p.4)

Palliative care: An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and

relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- provides relief from pain and other distressing symptoms
- affirms life and regards dying is a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance the quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (WHO, 1998, para. 1)

Terminal care (or actively dying): Maintenance of comfort and provision of support for the patient and family in the final hours, days or possibly weeks of life. (Middleton-Green et al, 2017, p.22)

Figure 1: End of life, palliative care and terminal care definitions

In this study 'end of life' describes the period of time before death that is likely in the next 6–12 months, but the person may live for years. 'Palliative care' is therefore the holistic care provided to someone with a life-limiting illness through to bereavement, with the aim of meeting all the individual's holistic needs and supporting their family or caregivers. Engagement with palliative care can occur at diagnosis. 'Terminal care' or 'terminal phase' describes the last hours or days, possibly weeks.

Frailty is a concept that is receiving an increased amount of scientific attention, which should lead to a better understanding of its inherent heterogeneity and complexity: 'In the past, the term frailty was used almost interchangeably with aging, disability, or comorbidity,

partly because of the similarity and high coexistence rate of these descriptive states. However, there are clear differences between frailty, aging, disability, and comorbidity' (Kojima et al, 2019, p.24).

As Kojima et al (2019) pointed out, frail older adults are the main users of medical and social care services. However, the chronic and complex health and social care needs of frail older people are not being met by health and social care services (Kojima et al, 2019). There has been a lack of consensus on the operational definition of frailty. WHO has conceptualised frailty as shown in Figure 2.

> Frailty may be conceptually defined as a clinically recognizable state in older people who have increased vulnerability, resulting from age-associated declines in physiological reserve and function across multiple organ systems, such that the ability to cope with everyday or acute stressors is compromised. (WHO, 2017, p.9)

Figure 2: WHO frailty definition

Seymour (2017) highlighted that due to these age-associated physiological declines and multiple comorbidities, 'care of older people' *is* 'end of life care' and older people constitute the largest number of patients in hospital but do not routinely receive palliative or end of life care (p.81). Bunt et al (2017) and Borgstrom (2016b) describe social frailty and social death respectively, which takes into account the fact that frailty is more than a biological or psychological domain but also a social one (see Section 2.6).

The original study protocol was to recruit participants through three acute hospitals. When that recruitment strategy proved unfruitful, recruitment moved to community hospitals – see Chapter 3, Section 3.4.2. Acute and community hospitals have a different role and purpose. Definitions have been included for clarity.

Community hospital

- A modern community hospital service aims to provide an integrated local health and social care resource for the local population to which it belongs.
- These local facilities develop as a result of negotiations between local people, practitioners and the NHS. Community hospitals are an effective extension to primary care, with medical support provided largely from local GPs.

- The service models include rehabilitation, palliative care, intermediate care and surgical care, plus emergency and maternity facilities.
- Community Hospital interventions ranging from day surgery to medical inpatient episodes are characterised by care pathways that maximise local sources of support, including those outside the NHS and health care professionals.
- This integrated systems approach and sense of devolved accountability places the community hospital as a focus of local community networks. (Tucker, 2016, p.1)

Acute hospital

Acute services include 'all promotive, preventive, curative, rehabilitative or palliative actions, whether oriented towards individuals or populations, whose primary purpose is to improve health and whose effectiveness largely depends on time-sensitive and, frequently, rapid intervention …The term *acute care* encompasses a range of clinical health-care functions, including emergency medicine, trauma care, pre-hospital emergency care, acute care surgery, critical care, urgent care and short-term inpatient stabilization.' (Hirshon et al, 2013, para. 3)

Figure 3: Community and acute hospital definitions

Community Hospitals have been part of the UK healthcare system for over 150 years and offer a strong tradition of care that local populations have known over generations. There are over 500 community hospitals throughout the UK. Originally established as converted cottages offering inpatient beds, they have developed into hubs of services that have developed to meet changing needs. These services range from health promotion, diagnostics, treatments, rehabilitation and end of life care.

Hospital discharge is a process whereby the patient transitions back to community living and the into the care of primary care in the community.

'Hospital discharge takes place on a day-to-day basis, and involves complex, interdependent functions that require interaction and coordination among a multidisciplinary team of stakeholders, i.e., doctors, nurses, receiving health-care providers, patients, next of kin, and patient coordinators' (Laugaland et al, 2014, p.4).

Laugaland et al (2014) identified ten common functions that constitute the daily routine for discharging older patients from the hospital to the community:

- Review of hospital inpatients – classifying patients that are medically fit for discharge
- Notifying the municipality that the patient is medically fit
- Informing the patient that they are ready for discharge
- Assigning an appropriate post-discharge site of care and notifying the hospital
- Notifying and informing the patient's next of kin (if any)
- Preparing a nursing discharge record
- Preparing a medical discharge letter
- Providing oral information about the transfer to post-discharge care providers
- Ordering transportation
- Transferring the patient to the post-discharge site of care and ensuring the transfer of written information (p.9)

Figure 4: Hospital discharge description

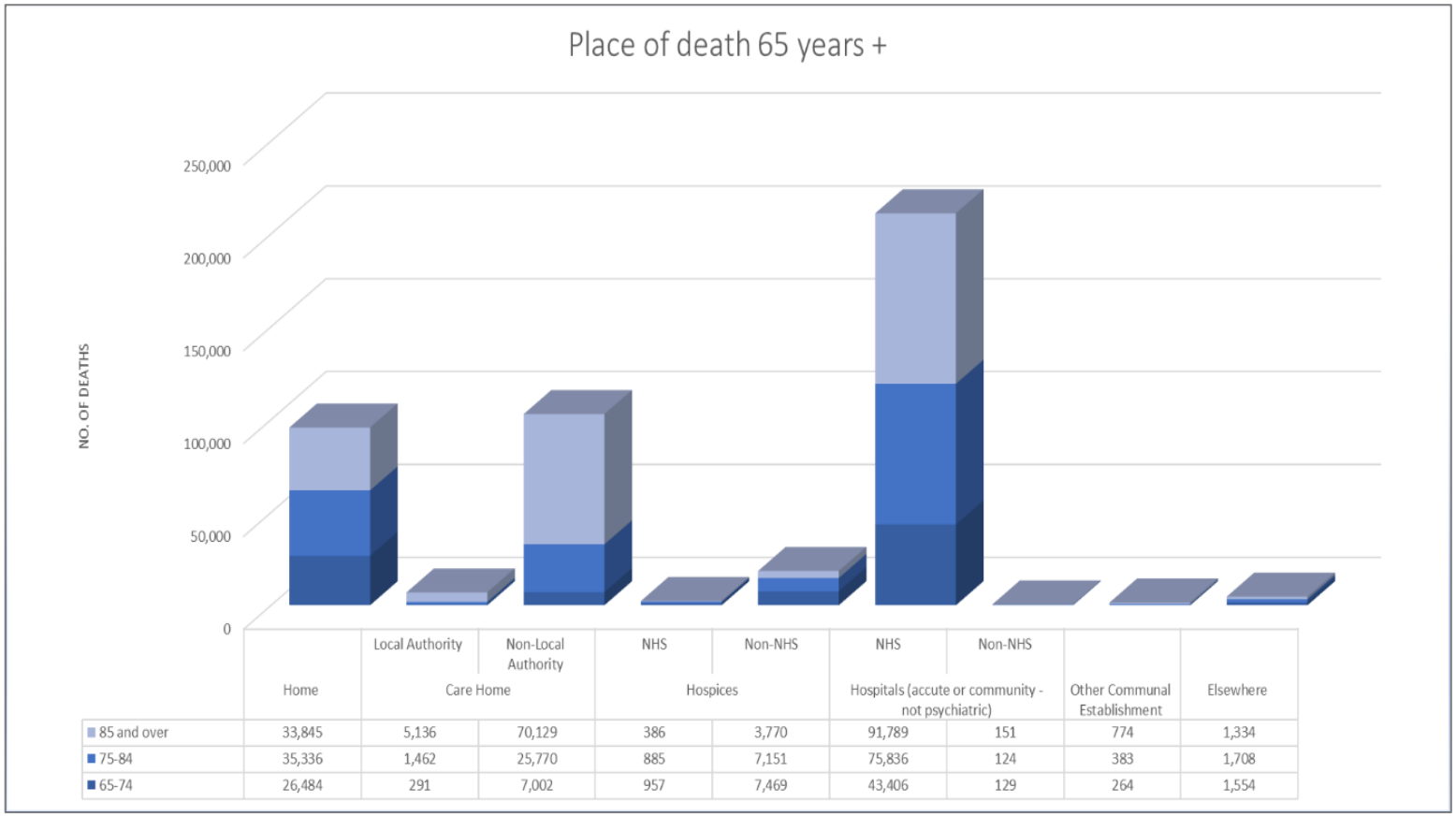
Hospital discharge has become a contentious issue, particularly with regards to older people whose transition can be delayed due to issues with arranging social care packages, care home places and intermediate care (community hospital) places that lead to 'delayed transfer of care' (Oliver, 2016). Oliver (2016) reported that between 2013 and 2015 there was a 31% rise in delayed transfers of care, which accounted for 1.15 million bed days. Some 85% of patients occupying those beds were aged over 65. Oliver (2016) stated that the issue topped the NHS finance director's list of concerns. It was estimated that the cost of delays to the hospital sector was £820 million per annum, compared to a hypothetical cost of alternative community services for all those patients of just £180 million (Oliver, 2016). This illustrates how discharge becomes a concern of not just health professionals, but also hospital management. It also shows how pressure from acute hospitals can be applied to community hospitals in order to relieve the burden of patients who are marooned in hospital awaiting a transfer of care.

2.3: Background

Societal responses to the dying past and present will now be presented, followed by an outline of end of life policy, together with relevant investigations, audits and literature. This leads to a review of the literature regarding discharge from hospital at the end of life, presenting stakeholder views and gaps in research.

2.3.1: Societal response to dying

How society treats and manages the dying puts the study into context and helps to identify future solutions and to avoid mistakes made in the past (Kellehear, 2011). Kellehear (2011) provides an excellent summary of the historical context of care of older people at the end of life starting with hunter-gatherer peoples. At this time, old people were seen as a 'problem' or a burden and people 'showed respect' through neglect, abandonment or killing in the form of 'assisted dying'. Whilst still able to provide social memory, stability and leadership, older people were perceived as productive members of the group (Kellehear, 2011). However, dependency and frailty caused vulnerability, and once illness, disability or dependence rendered the older person unproductive they were assisted to die. The notion of assisted dying did not disappear as pastoral societies developed, but unproductive members of society fared better in farming and handicraft economies, with the older people living either with or next to family. In these circumstances it fell to the female family members and children to care for the older person. Kellehear (2011) points out that the industrial revolution brought about mass migration to the cities and a change in the provision of housing and food as well as networks of kin. This resulted in large numbers of older people being institutionalised in 'poorhouses', 'almshouses', 'workhouses' and other institutions for the old and infirm. These institutions played a role in end of life care of the older people. Quoting Pelling and Smith (1991), Kellehear surmises that the modern development of institutions specifically for the older people is the 'only demonstrable growth' in their care. Figure 5 shows a sample of the statistics published by the Office for National Statistics (2017), which illustrates the place of death for individuals over 65.



	Home	Care Home: Local Authority	Care Home: Non-Local Authority	Hospices: NHS	Hospices: Non-NHS	Hospitals (accute or community - not psychiatric): NHS	Hospitals (accute or community - not psychiatric): Non-NHS	Other Communal Establishment	Elsewhere
85 and over	33,845	5,136	70,129	386	3,770	91,789	151	774	1,334
75-84	35,336	1,462	25,770	885	7,151	75,836	124	383	1,708
65-74	26,484	291	7,002	957	7,469	43,406	129	264	1,554

Figure 5: Place of death for individuals 65 and over in 2016 (ONS, 2017)

Figure 5 illustrates that of 443,535 deaths of individuals aged over 65, 211,435 were in hospital, 109,790 were in care homes, 95,665 were at home and 20,618 in a hospice. Therefore, 77% of individuals over 65 died in either a hospital or a care home. Consequently, much like the older people of the industrial revolution, most of our dying are cared for in institutions. However, the standards of accommodation and food are significantly improved. Nevertheless, with regard to care and nursing homes, inequality of access to services arises from means testing. Gawande (2015) describes the origins of nursing homes from the USA perspective, which again began with poorhouses. It was assumed that the introduction of the Social Security pension in 1935 would enable the older people to support themselves and not rely on poorhouses. However, when people were too frail to take care of themselves they still ended up in the poorhouse. Gawande (2015) conveys that as hospitals 'sprang up', they became the place to put these individuals too frail to remain at home and the poorhouses emptied. However, by the 1950s the hospitals were filling up with conditions associated with frailty that could not be resolved and funding was made available for patients needing an extended period of 'recovery'. Gawande (2015) points out that nursing homes were therefore never intended to help people facing dependence in old age, rather to free up hospital beds. These institutions are described as prioritising medical goals such as the avoidance of bedsores and maintaining weight. Comparing these institutions to prisons, Gawande (2015) is critical of how they do not allow residents to live a rich and fulfilling life due to the restrictions of procedures and protocol, which are for the benefit of the institution rather than its residents. It is no wonder then that there remains the pervasive shame of institutionalisation and physical disability, and fear of being a burden to family physically, emotionally and financially (Lloyd, 2011; Kellehear, 2011; Pollock, 2015).

Over the past five decades compassion for, and communication with, the dying has been perceived as a problem. The 1965 US study *Awareness of Dying* by Glaser and Strauss (the first application of the grounded theory methodology) sought to contribute toward creating end of life care that was more rational and compassionate (Andrews, 2012). In the study they looked at how aware the dying were of their impending death. They found that those who had 'closed awareness' of their prognosis received only the necessary nursing care in order to prevent them from having an 'open awareness'. Therefore, the awareness of the patient had an impact on the interaction with health professionals and the quality of care they received. Glaser and Strauss found that Americans at that time hesitated to talk openly about dying and were prone to avoid telling a person that he or she was dying. Yet

communication between health professionals, the dying and their family enables advance planning and choice, a key concept in the policy discussed below.

At the same time that Glaser and Strauss were producing *Awareness of Dying*, the modern hospice movement was in its infancy. The hospice movement has worked to change the culture of care for the dying in the UK.

2.3.2: Hospice movement

In the 1960s the term 'hospice' was used to describe specialist care at the end of life. The term can be traced back to medieval times as being a place of rest for ill or weary travellers (NHPCA, 2016). Hospices were prevalent in the Middle Ages but declined and then were revived in France as well as in Ireland when The Sisters of Charity opened Our Lady's Hospice in Dublin in 1879. They also opened St Joseph's Hospice in London in 1905, where Dame Cicely Saunders worked. Her work there led to the creation of the modern hospice movement in 1967, with the opening of St Christopher's Hospice. This was a watershed moment for care of the dying in UK, where expert pain and symptom control were combined with compassionate care, teaching and clinical research (St Christopher's, 2017). Dame Cicely recognised the importance of not only excellent medical and nursing care but also 'holistic' support that included practical, emotional, social and spiritual needs (St Christopher's, 2017). The dying person and the family were seen as a unit, and bereavement services were developed at St Christopher's Hospice to extend support beyond the death of the patient. In 1969 Dame Cicely founded the first home care team, taking palliative care into the community (St Christopher's, 2017). This also signalled the beginning of specialist support for the dying in the community. The majority of hospice care (80%) is now in the community, with 200,000 people with terminal and life-limiting conditions accessing hospice care in the UK each year (Hospice UK, 2017). Bereavement services also developed through the holistic hospice approach. Some 40,000 people in the UK receive bereavement support from hospices each year (Hospice UK, 2017).

Limitations of hospice care were reported in the Care Quality Commission report 'A different ending' (2016), which reported that whilst cancer was the cause of '29% of deaths in England and Wales in 2014, just 7.7% of all deaths in hospice inpatient units between 2008 and 2012 were from conditions other than cancer'. Furthermore, the review found that people with conditions other than cancer are not always able to access specialist palliative care services when needed, and that 'generalist care is not always good enough' (CQC, 2016). As Pall and

Manning (2014) stated, 'the palliative care needs of older people are often under assessed and undertreated'.

2.3.3: Compassionate communities

A recent development in the care of the dying is described by Kellehear (2013) as 'compassionate communities', which is a public health approach to palliative care that has influenced policy; for example, 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020' (National Palliative and End of Life Care Partnership, 2015), which will be discussed further in the policy overview in Section 2.4. Abel and Kellehear (2016) proposed this approach as they felt that palliative care tends to confine its attention to medical and nursing workforce demands, which is a major retreat from the basic vision of palliative care as 'a promise of physical, psychological, social and spiritual care delivery at the end of life' (p.21). They suggest that the narrowing of priorities in this way is also a failure of the capacity to use public health models. These models have proven effective in other health service areas as well as end of life care (O'Mara-Eves et al, 2013; Sallnow et al, 2016). Abel and Kellehear (2016) propose that using a public health approach to palliative care could support the shortfalls in the traditional ways of offering social support at the end of life: 'We do well to remember that death, dying, caregiving and loss are social problems with medical aspects to them and not medical problems with social aspects. Viewed in this way, it is crucial that we seek social solutions to make the experience as meaningful and supportive as possible' (Abel & Kellehear, 2016, p.23).

Another aspect of a public health approach to palliative care is increasing community engagement. For example, charities such as National Council for Palliative Care (NCPC) and Macmillan are keen to engage the public to tackle death as the 'the last taboo'. It is highlighted that the lack of conversation around death and the dying person's wishes creates a barrier to providing good care at the end of life, as well as preventing the person's wishes from being carried out. Kellehear (2011) emphasises that 'community' is not just the site of the patient or the service, but the social network within which the patient resides and interacts. With this in mind, the next section examines what areas policy considers important when delivering good end of life care.

2.4: National policy overview

Kellehear (2005) suggests that, 'It is vital that governments … provide some policy leadership in the development and practice imperatives around public health approaches to dying,

death and loss if only to coordinate and maximise diverse service and community responses to death' (p.29). The following section of this chapter presents an overview of the policy and discourse over the last 15 years. It will provide a critique of this discourse, drawing on relevant articles and third-sector publications, as well as local and national policy. The chapter will conclude highlighting current discourse and policy failures around end of life care, making a case for the research questions of this study. This will lead on to a summary of the current literature in relation to the research questions of this study.

2.4.1: Demographic and morbidity changes

With a rapidly ageing society and changing patterns of illness, many more people will live longer and with long-term conditions. Therefore, each year more of us will die and many more of us will face the challenges of dying, death and bereavement. In the next 20 years the number of people aged over 85 is expected to double. Furthermore, there is also an expected increase in the number of centenarians, increasing eight-fold to 100,000 by 2035. Meanwhile, there is evidence of growing numbers of young adults with life-limiting conditions and highly complex needs moving from children's services into adult services (Hospice UK, 2017). Recruitment and data collection for my study took place before the coronavirus pandemic. The effect that the pandemic has had on older people is well documented, but at present there are no statistics regarding changes in the demographics of people over 85.

Individuals with complex health and social care needs put a strain on hospitals, particularly around discharge when the transfer to community services for health and social care support need to be put in place. The Royal College of Physicians published a letter stating that the increase in patient need is outpacing the resources available, that services are 'too often paralysed by spiralling demand to transform and modernise', hospitals are 'over-full, with too few qualified staff' and services are 'struggling or failing to cope', and there are 'increasing reports of staff contemplating the sad decision to leave the NHS' (RCP, 2017b, para. 3). Furthermore, that 'current investment levels are not sufficient to meet current or future patient needs' and the immediate actions needed are 'the reinvigoration of social care services and urgent capital investment in infrastructure' (RCP, 2017b, para. 4).

The following section comprises a review of current policy, which is necessary in order to ascertain the 'vision and past benchmarks of progress' within which this study sits (Groundswell Project, 2018, 35:25).

2.4.2: Policy timeline

Figure 6 provides a summary of national policy starting with the *Mental Capacity Act* in 2005 (DoH, 2005) through to 2019. Running parallel to these are relevant reviews, charity position statements, articles and books. A list of the documents with full titles can be found in Appendix 1.

In 2005 the *Mental Capacity Act* (DoH, 2005) began the conversation about capacity, as well as providing a legal framework to support people's choices and preferences for their care. This then provided the basis for advance care planning and advance decision to refuse treatment. In 2008 *The End of Life Care Strategy* was published by the Department of Health. The Strategy had a broad vision, and explicitly took a 'whole systems' approach to drive improvement. It was ambitious for end of life care, arguing that the way we care for dying people says something fundamental about our values as a society, as well as the health and care system: 'How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services' (DoH, 2008, p.10). After this came the *Five Year Forward View* (DoH, 2014), which only briefly mentions end of life, and that was after lobbying from concerned parties. Northern Ireland, Wales and Scotland produced regional documents (Department of Health, Social Services and Public Safety, 2010; NHS Wales Health Board, 2013; NHS Scotland, 2008) that have been superseded by 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020' (National Palliative and End of Life Care Partnership, 2015) ('Ambitions').

'Ambitions' has taken a different approach in its development and its vision. The document was developed in partnership with national organisations across the statutory and voluntary sectors. It set out 'our vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England' (National Palliative and End of Life Care Partnership, 2015, para. 3). It called upon local leaders and professionals to act in order to meet the challenges of the increased needs of an ageing population at the end of life; urging for a shared ambition and urgency in improving care at the end of life, and that local documents should be generated based on 'Ambitions'.

'Ambitions' has also taken evidence and patient voice into consideration in the development, as well as concepts of Compassionate Communities, which is most obvious in Ambition 6: 'Each community is prepared to help' (p.35). 'Ambitions' mentions public health approaches to palliative care and that there is a need for them to be 'accelerated and

support given to people and communities who can provide practical help and compassion'. Guidance on how this may be achieved is not given, perhaps leaving it to be taken forward by local organisations who know their local community best. However, the framework highlights that the variation in quality of care at the end of life has become a point of national debate and that while death may not be a failure, poor care is.

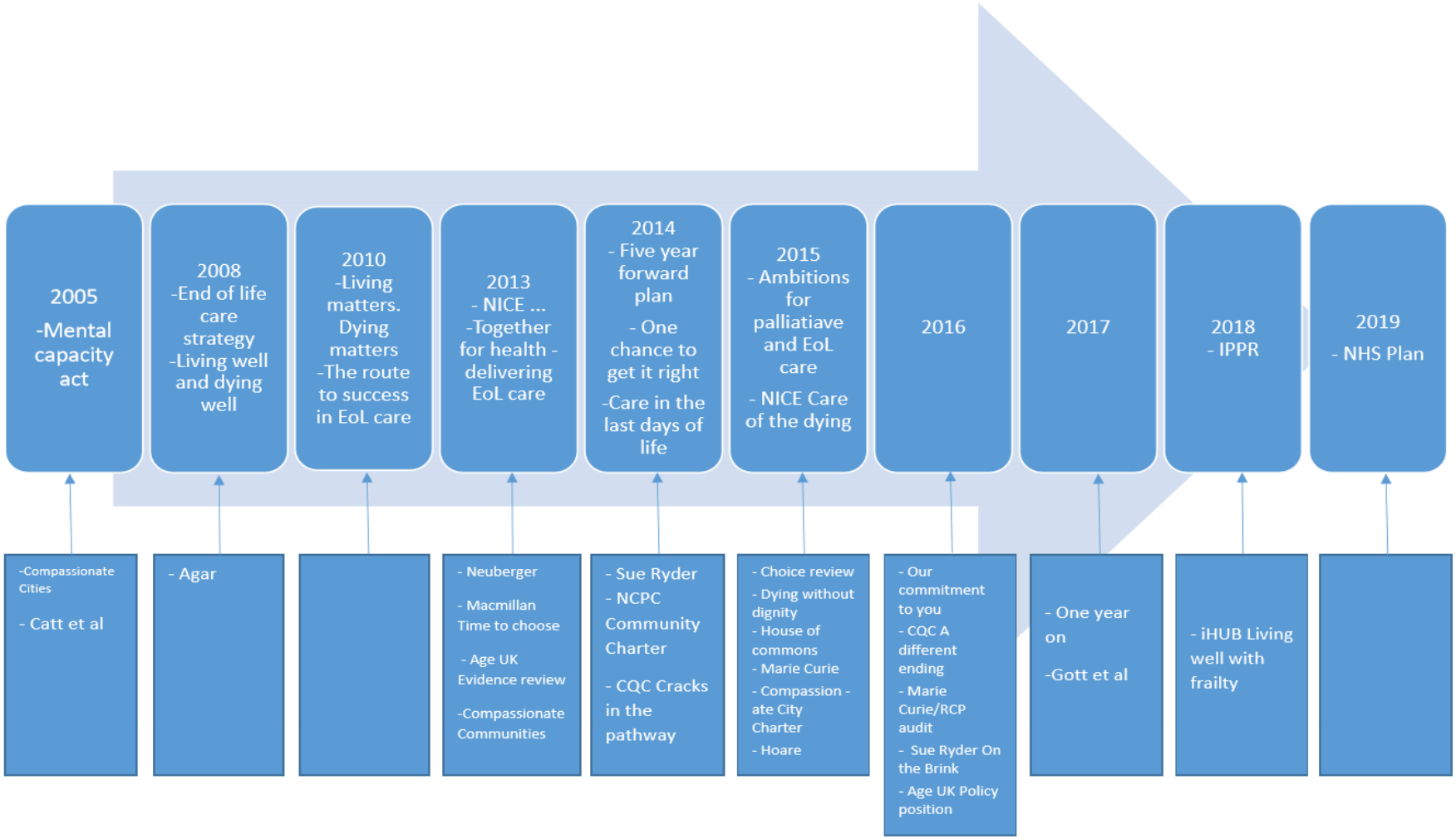


Figure 6: Policy timeline

2.4.3: Policy identification of continuing variation in care

Unacceptable variations in access to and quality of palliative care is a dominant theme, in policy as well as in third-sector reviews (CQC, 2016; NHS England, 2014; DoH, 2014; House of Commons Health Committee, 2015; DoH, 2016; DoH, 2017; IPPR, 2018; Neuberger, 2013; Age UK, 2016; The Choice in End of Life Care Programme Board, 2015; Abel & Kellehear 2016; Parliamentary and Health Service Ombudsman, 2015; Leadership Alliance for the Care of Dying People, 2014).

'Ambitions' (National Palliative and End of Life Care Partnership, 2015) summarised what is already known:

- People from black and minority ethnic (BAME) communities and deprived areas report a poorer quality of end of life care; similarly, those who are living with non-malignant illnesses, people living in more deprived areas, the homeless or imprisoned, and those who are more vulnerable or less able to advocate for their own care.
- The quality of end of life care is poorer and harder to access for people who live in very rural or other isolated areas.
- There remain unacceptable inequities and inequalities in access to palliative and end of life care particularly for those with learning disabilities, dementia and non-malignant long-term conditions. (National Palliative and End of Life Care Partnership, 2005, p.21)

The Parliamentary and Health Service Ombudsman (2015) reported that complaints that were 'recurring and consistent' included: lack of recognition that people were dying and lack of response to their needs; poor symptom management; lack of communication; lack of access to care out of hours; poor planning; and referrals and care transfers were delayed.

NHS England's *Actions for End of Life Care: 2014–16* also highlights the variation in expenditure on specialist palliative care between Primary Care Trusts across the country. In 2010–11 it was reported that expenditure ranged from £186 to £6213 per death. Furthermore, the voluntary sector provided a 'considerable proportion' through fundraising.

Though not specifically discussing palliative care, *The Five Year Forward View* (DoH, 2014) illuminates a wider problem regarding inequity of care. It refers to events at Mid-Staffordshire and Winterbourne View when discussing 'unacceptable variations of care provided to patients, which can have devastating effects on individuals and their families' (p.7).

The documents reviewed illustrated recurring themes regarding what constitutes good end of life care and how care can be improved, which will be presented in the next section. They also provided evidence of repeated issues with end of life care.

2.5: A thematic policy analysis

An analysis of the themes that constitute good end of life care is now presented, followed by how these themes have been interpreted in local documents. Changes in discourse and rhetoric used in policy are mapped. A thematic analysis was chosen in order to analyse the policy data and to identify themes, or patterns of meaning, within policy relevant to the end of life phase. Braun and Clark (2013) state that it is 'theoretically-flexible' and can therefore be used within different frameworks. In this case thematic analysis is used both to reflect the explicit content of the data and to report concepts and assumptions underpinning the data. Furthermore, in keeping with constructivist grounded theory, there was a focus on how a certain reality and discourse regarding end of life is created in the policy. The themes of policy help to explicate the dominant discourses and how the 'truths' created by government are conveyed. In an interview Foucault said,

> *Truth isn't outside power, or lacking in power ... Truth is a thing of this world: it is produced only by virtue of multiple forms of constraint. And it induces regular effects of power. Each society has its regime of truth, its 'general politics' of truth: that is, the types of discourses which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true.* (Truth and Power: an interview with Michel Foucault, 1979, p.131)

The later thematic literature reviews help to illustrate how more marginalised voices of individuals, such as patients and their carers, may have a different priorities and realities to those portrayed in policy.

2.5.1: Describing good end of life care

When describing good end of life care, there are some recurring themes: 24/7 access to or provision of support; service development or integration; development of professional knowledge; more information sharing either through conversations or via technology; advance care planning; and being at home.

2.5.1.1: 24/7 access to or provision of support

In 2008 *The End of Life Care Strategy* (DoH, 2008) stated that 'medical, nursing and personal care and carers' support services can be made available in the community 24/7', which can be accessed without delay, particularly in the last days or weeks (p.13). It asserted that 'it is evident that provision of 24/7 services can avoid unnecessary emergency admissions to hospital and can enable more people at the end of their life to live and die in the place of their choice' (p.13). This theme of 24/7 access to specialist support continues through the policy and reviews all the way to 'Ambitions' (National palliative and end of life partnership, 2015). This theme also features in NICE guidelines 'End of life care for adults', which suggests care being coordinated across organisational boundaries 24/7 and that information is shared across boundaries in an emergency (NICE, 2011). The proposed mode of sharing across boundaries is an Electronic Palliative Care Coordination System (EPaCCS).

In 2013–14 *More care, less pathway* (Neuberger, 2013), NCPC (2014) and Macmillan (2013) were all critical of the lack of 24/7 palliative care services available in the community as well as social care and support for carers. In 2016 'Our commitment to you' (House of Commons Health Committee, 2015) reviewed best practice and described how some CCGs were commissioning 24/7 specialist nursing services 'backed by social motivated investment' that promised to deliver 'improved quality and choice in community-based end of life care'. This indicated some movement towards the direction promised in *The Care Bill* (DoH, 2013). Yet in 2016 CQC's *A different ending* continued to call for 'timely, equitable access 24/7 support'. Also included in their definition of good end of life care were 'identification of people likely to be in the last year of life', 'coordination of care' and 'care in the last days and hours that delivers the five priorities of care'. The five priorities were identified after *More care, less pathway* (Neuberger, 2013) found serious problems with the Liverpool Care Pathway and advised that it was no longer used. The five priorities were created to guide care of the dying in the last days or hours and were published in *One chance to get it right* (Leadership Alliance for the Care of Dying People, 2014).

The 'Five Priorities for Care' are that, when it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Figure 7: The Five Priorities of Care in *'One Chance to Get it Right' (Leadership Alliance for the Care of Dying People, 2014, p.7)*

In summary, while 24/7 care has been articulated as a policy imperative, and exemplars of implementation provided, a continuing critique of the lack of 24/7 by such bodies as CQC suggests that this particular policy priority is not consistently embedded in practice.

2.5.1.2: Service development towards integration

In order to meet the target of improved palliative care services, the development of integrated service provision or integration of existing services is another key theme evident from policy. The *End of Life Care Strategy* (DoH, 2008) described individual services and discrete service aims that meet the needs of those at the end of life. However, at this stage there was no emphasis on integration of, or collaboration between, services. Whilst not end of life specific, the 2014 the *Five Year Forward View* (DoH, 2014) supported new care models that involve collaboration across all sectors. For example, a new care model is discussed where primary and acute care are integrated, which would provide a more seamless service as individuals move from the community to hospital and then home again. The Kings Fund report 'Implementing the NHS five year forward view: Aligning policies with the plan' (Ham et al, 2015) continues to recommend new care models and the removal of barriers to their development. The report highlights the major challenges that providers face when putting greater emphasis on integrated care and when providers come together in alliances and networks to deliver care. The report emphasises funding and leadership as key barriers to new care models.

The most recent policy document regarding palliative care, 'Ambitions' (National Palliative and End of Life Care Partnership, 2015), called for the development of community partnerships and a 'system-wide' response to dying people 'using a full range of coordinated services deployed in the community' (p.29). In *Our commitment to you for end of life care: The Government response to the review of choice in end of life care* (DoH, 2016), development of services is highlighted as a way of providing 24/7 access, and in the same year CQC's 'A different ending' also emphasised services and initiatives to support improvement in the quality of personalised end of life care for specific groups, including new models of care. Examples of good practice for others to learn from are also provided.

In the 2018 Institute for Public Policy Research (IPPR) briefing paper 'End of life care in England' (IPPR, 2018) the fragmentation of commissioning caused by legislation, introduced through the 2012 'Health and Social Care Act', has been identified as a barrier to integration of services. However, the report goes on to highlight that the introduction of 'Sustainability and Transformation Plans' (STPs) may lessen the impact of the 2012 Act. STPs were identified as having led to the development of 'many ambitious and promising solutions for reforming health and care', but caution that local partners 'face a number of challenges to putting these into practice'. STPs were announced as part of NHS England's 'NHS planning guidance 2016/17 – 2020/21'. Along with the government's mandate to NHS England for 2016–17, these documents created a new funding environment for NHS providers that aims to achieve collaboration rather than competition. To receive funding, providers have to demonstrate that they have worked with each other, commissioners, the public and local authorities to create plans that will address the three gaps identified in the NHS *Five Year Forward View*: health and wellbeing; care and quality; finance and efficiency (RCP, 2017). This represents a shift from central and segregated to local and integrated services.

The IPPR briefing paper (2018) goes on to discuss how more funding and investment in long-term care services results in a 'reduction in hospital admissions'. They urge that increasing public investment in long-term care in England to a level that corresponds with countries with more developed infrastructure for long-term care, 'could result in a significant decrease in the proportion of people who die in acute care settings' (p.14). They draw on the examples of the Netherlands, Sweden and Switzerland and note that if the proportion of deaths that occur in hospital in England was as low as it is these countries, 'it could mean that as many as one in three of those who currently spend their final days in a hospital might be treated at home or in the community' (p.14).

2.5.1.3: Professional knowledge and development

The *End of Life Care Strategy* (DoH, 2008) places heavy emphasis on workforce and professional development rather than service development. It called for a major workforce development initiative, with particular emphasis on staff for whom end of life care was their only aspect of work. This was to take the form of communication skills training programmes and 'other programmes based on the competences needed by different staff groups' (p.12). This training was to ensure that 'health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying' and is seen as 'critical to the success of improving end of life care' (p.14). The theme of the development of staff communication skills and competencies continues through the literature (NICE, 2011; Leadership Alliance for the Care of Dying People, 2014; NICE, 2015; National Palliative and End of Life Care Partnership, 2015; DoH, 2016; CQC, 2016).

In the report *More care, less pathway* (Neuberger, 2013), communication and inexperience were found to be one of the main failings in the delivery of palliative care. The report advised that 'clinicians should be required to demonstrate proficiency in caring for the dying' as well as the development of resources and programmes for continuing professional development (p.10). Doctors and nurses are mentioned in relation to professional development and training, but no other healthcare professionals or support staff.

The House of Commons Health Committee in their report on end of life care (2015) stated that in order for effective end of life conversations to take place the workforce should be well-trained and supported. The report references The Royal College of Nursing (2014) survey findings in which its members voiced serious concerns about their abilities to deliver high-quality end of life care to dying people. In the survey, just '10.5% of nurses felt they were always able to deliver the right level of care to individuals, while almost 70% had experienced people being admitted to hospital at the end of their life due to a lack of resources to treat them in a community setting, despite this being against their wishes' (p.21). A Royal College of Physicians (2012) survey is also referenced. This survey found that 'only a third of respondents had attended any learning event on end of life care in the last five years' (p.21). The survey also found that doctors reported a lack of support from their employers as well as a demand for continued professional development in end of life care. The IPPR (2018) briefing paper also found that staff training and development has been identified as a necessary first step to increasing the number of people offered end of life care.

The main area of staff development that is referenced in the policies is communication skills. It is felt that if clinicians can communicate more effectively with patients regarding their end of life wishes, there will then be an increase in patients expressing their wishes, making advance care plans and discussing their wishes with family. This in turn can have an impact on the patient's preferred place of care and death being met. The following section looks in more detail at the theme of information sharing to improve care at the end of life.

2.5.1.4: Information sharing, conversations and use of technology (EPaCCS)

Information sharing includes the exchange of information between patient and clinician, between health professionals and across organisational boundaries and is seen as key to improving care for those at the end of life. Changes in policy discourse can be mapped, with the term 'communication' being used in earlier documents and a more recent shift to terms such as 'information sharing', 'collaboration' and 'conversations'. As mentioned earlier, poor communication is linked with poor palliative care, hence the emphasis on communication skills training.

The *End of Life Care Strategy* (DoH, 2008) is the first to focus on the development of an electronic means of sharing information. The Electronic Palliative Care Coordination Systems (EPaCCS) holds information about a person's care and preferences that can be shared with different professionals. Macmillan (2013) argue that the use of this technology and the sharing of information are crucial to good coordination of care. They report that where implemented, 'EPaCCS have helped as many as 80% of people registered to die in their preferred place' (p.12). An economic evaluation carried out by NHS England (2013) estimated yearly savings of up to £133,200 per year, per 200,000 head of population where EPaCCS are used. Although there has been progress regarding the implementation and use of EPaCCS, many areas in England are still not covered (Macmillan, 2013).

EPaCCS is stressed as a tool to improve the quality of care at the end of life throughout the literature (NCPC, 2014; NHS England, 2014; National Palliative and End of Life Care Partnership, 2015; House of Commons Health Committee, 2015; CQC, 2016; DoH, 2016; DoH, 2017; IPPR, 2018). The literature also highlights the consequences of an underdevelopment of EPaCCS, resulting in a significant barrier to information sharing (CQC, 2016). EPaCCS together with a care coordinator is also believed to enable more people to experience good, personalised care at the end of life, as they ensure the care is coordinated around the individual (CQC, 2016). NCPC (2014) add that where EPaCCS is used there is evidence that there is better identification of people at the end of life. Furthermore,

conversations about choices at the end of life are facilitated and recorded. It is then possible to share these preferences and, for example, avoid unwanted hospital admissions.

The House of Commons Health Committee review (2015) recommended the Government encourage and monitor the take up of electronic care planning and EPaCCS in order to facilitate information sharing between providers. Additionally, that Government review the best mechanisms to facilitate the understanding and take up of EPaCCS and explore options for a universal standard template for use across England. In 2017, *One year on: The Government Response to the Review of Choice in End of Life Care* (DoH, 2017) stated that 'greater personalisation' can be achieved with use of EPaCCS. In 2017, however, it is stated that the 'full roll out of EPaCCS remains one of the key objectives of NHS England's regional palliative and end of life care leads, working in conjunction with colleagues from NHS Digital' (DoH, 2017), which suggests there is still a way to go (p.8).

The themes discussed so far of service access and development, development of staff and technology corroborates Abel and Kellehear's (2016) assertion that palliative care tends to confine its attention to medical and nursing workforce demands, which is a major retreat from the basic vision of palliative care as 'a promise of physical, psychological, social and spiritual care delivery at the end of life' (p.24). However, EPaCCS is considered the 'pre-eminent initiative in enabling advance care planning' and could provide a tool for making sure an individual receives holistic care (Petrova et al, 2016, p.447). The theme of advance care planning is now considered.

2.5.1.5: Advance care planning

'Advance care Planning: a guide for health and social care staff' (NHS End of Life Care Programme, 2007) first outlined that advance care planning (ACP) was a process that involved a voluntary discussion between an individual and their care provider, about future care plans. Details of what an ACP discussion should include is illustrated in Figure 8.

An ACP discussion might include:

- the individual's concerns and wishes,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

Figure 8: NHS end of Life care Programme, 2007, p.4

The *End of Life Care Strategy* (DoH, 2008) proposed that ACPs are a heuristic tool for recording the person's preferences regarding both the type of care they would wish to receive and the setting or location in which they wish to be cared for. Advance care planning continues to be supported as a means to facilitating communication, gathering patient wishes and ultimately enabling the individual to be cared for and to die in their preferred place (DoH, 2008; NICE, 2011; Macmillan, 2013; NHS England, 2014; DoH, 2016; CQC, 2016; IPPR, 2018; National Palliative and End of Life Care Partnership, 2015; The choice in end of life care programme board, 2015; House of Commons Health Committee, 2015; Abel et al, 2016). Indeed, *One chance to get it right: Improving people's experience of care in the last few days and hours of life* (Leadership Alliance for the Care of Dying People, 2014) says that ACP is a priority for the dying person.

What's important to me. A Review of Choice in End of Life Care (The Choice in End of Life Care Programme Board, 2015) places a great deal of emphasis on advance care planning to encourage early discussion and information sharing to enable individuals to have 'choices'. ACP is also considered to increase the likelihood of individual's wishes being met. Whilst there is evidence to suggest that using ACP to gather an individual's wishes regarding their care at the end of life can increase the likelihood of those wishes being met, Macmillan caution that anecdotally there is variable uptake of ACP across England (Macmillan, 2013; IPPR, 2018).

'Ambition 6: each community is prepared' of 'Ambitions' (2015) includes ACP under the heading of public awareness. The report recommends that the public is educated how to, and encouraged to, create wills and advance care plans. NCPC (2016) add that as part of public health approach to care at end of life, there needs to be community development to

support the dying and those around them. This includes support to engage in advance care planning, do not attempt cardiopulmonary resuscitation (DNACPR) orders and the instatement of a power of attorney. These aspects of public involvement are believed to improve care at end of life by having wishes recorded and a person identified who can act on your behalf regarding health and/or finical issues if you lose capacity.

2.5.2: Place of care and death

The *End of Life Care Strategy* (DoH, 2008) placed a high value on receiving care from family and dying at home, with an implicit link to good care and a good death. However, this sets up a dichotomy of death at home versus the impersonal, routine death in an institution. The *End of Life Care Strategy's* (2008) emphasis on a good death at home as opposed to a bad death in hospital, initially triggered rhetoric which continued through subsequent documents, most noticeably in charities (Neuberger, 2013; Macmillan, 2013; NCPC, 2014;; House of Commons Health Committee, 2015; Age UK, 2016; Abel & Kellehear, 2016).

Over time the rhetoric regarding death at home has evolved. For example, 'Ambitions' (National Palliative and End of Life Care Partnership, 2015) focus on a public health approach to end of life care has marked a shift from equating a good death with dying at home, towards a less specific but more global aim of making 'deaths at home more achievable' (p.30). This change in rhetoric may also reflect that people may change their minds as their disease progresses, preferring the perceived safety of a hospital, or a perception possibly based on previous experience that adequate care will not be provided in the community (Pollock, 2015). Furthermore, in their literature review, Hoare et al (2015) drew attention to the fact that the *End of Life Care Strategy's* (DoH, 2008) assumption that 'most people would prefer to die at home' is misleading, as this is based on surveying the general public. Hoare et al (2015) point out that the preferences of the general public may be quite different to the view of dying patients as their priorities are different. For a well member of the general public, it is a hypothetic situation, whereas for a person with a life-limiting illness it is a real situation. In their literature review Hoare et al (2015) set out to assess patient preferences of place of death by examining the extent of unreported preferences, the importance of factors such of place of care and health diagnosis, and who reports preferences. The review found that the proportion of UK patients who want to die at home is unknown. Additionally, there was little similarity between the perspectives of the general public or family caregivers and the varied wishes of patients' preferred place of death. 'Preferences may be contextualised by where participants are being cared for when they are asked their

preferences. Ultimately, preferences for place of death appear to depend on who is asked the question; what, where, why and when they are asked; and how those without an answer are included' (Hoare et al, 2015, p.13). Qualitative evidence indicates that patients' attitudes to place of death are 'complex, uncertain, shifting and pragmatic' (Pollock, 2015, p.1). Furthermore, there is evidence that carer views differ from patient views, as carers are more likely than patients to opt for death away from home and in retrospective accounts often consider hospital to have been an appropriate place of death (Pollock, 2015). Pollock (2015) in their review of the evidence regarding home as the best place to die, was critical of the 'unreflective focus' when place is the determining factor of a good death. Furthermore, it distracts from the experience of the dying person. The domination of this model of a good death has also been shaped by responses to cancer and has been found to have limited applicability to other groups (Gott et al, 2008). A death occurring at home does not indicate whether the individual experienced pain, distress or fear (Pollock, 2015). Nor does it consider the experience of the main caregiver, who may have found the death at home deeply traumatic. Gott et al (2008) argues that for older people with chronic conditions this model also prevents professional and public engagement with different ways of seeing their needs. 'Idealised accounts of the good death at home often do not recognise the reality … the sheer hard work of dying' (Pollock, 2015, p.1).

Similar to 'Ambitions', later documents have developed a more nuanced approach to what home or community are, which is in keeping with the public health approach. This shifts the view of community as a place where the patient resides, to community as Kellehear (2005) describes it: 'a set of specific networks that are capable of sharing the burden of care in practical ways beyond members of the family' (p.49). The 'home is best' rhetoric and the themes discussed above fail to consider the complexities of people's lives and social networks. In a Dutch study, van der Heide et al (2007) found that having informal care support was a strong determinant of being able to die at home and that living with a partner was significantly associated with place of dying. Importantly, they also found that a substantial amount of the terminally ill in their study had no preference for their place of death. Stajduhar et al (2008), in a Canadian study, also found that many of their seriously ill subjects had no preferred location for death, be it home or hospital. They also found a difference between cancer and non-cancer diagnoses, with family of non-cancer patients preferring a hospital death. Gomes et al (2015) found that most patients dying of cancer would prefer to die at home, which is supported by family. However, this wish is 'seldom met'. Access to services does feature in research on preferred place of death in reference to

previous experiences. Previous poor experiences of services together with fear of dying at home alone and in pain influences the older people to choose to be admitted to hospital, rather than risk not being cared for (Catt et al, 2005; Agar et al 2008).

There has also been criticism of using place of death as a measure of a good death. *Actions for End of Life Care* (NHS England, 2014) refers to the studies in which over 60% of people would prefer to die at home, but acknowledge that not all these individuals were ill. The document goes on to state that place of death is an important driver for improving end of life care, but highlights that it is not necessarily everybody's highest priority. With reference to a population-based study involving just under 10,000 adults across England, they state that 34% rated 'dying in preferred place' as their priority. 'Having as much information' as they wanted and 'choosing who makes decisions' about their care were equally important (NHS England, 2014, p.8). The fact that the preferred place of death may change is also acknowledged based on the 2012 *British Social Attitudes* survey (Park et al, 2013). This study found that 60% would change their mind regarding dying at home if there was insufficient support from family, friends and health or social care. Other important aspect of their care at the end of life included the need to be pain free (24%) and the presence of family and friends (28%). These aspects of care are not so easily measured and are more subjective. Furthermore, as Pollock (2015) points out, 'A stated preference for home may constitute a positive choice. Alternatively, it may be regarded as the least bad option' (p.2).

More recently, the emphasis has been on choice together with control.

2.5.3: Choice and control

Policy discourse is often illuminated by particular words threaded through the document. Of particular note is the shift from words such as 'dignity', 'respect' and 'privacy', giving way to 'choice', 'control' and 'personalisation' in later documents.

2.5.4: Control

'Control' was previously only mentioned in terms of symptom or pain control, as in the *End of Life Care Strategy* (DoH, 2008), but takes on new meaning in later documents such as 'Ambitions' (National Palliative and End of Life Care Partnership, 2015), where it is seen as vital in the individualisation of care. 'Individualisation' and 'personalisation' are closely related to 'control' in the policy (National Palliative and End of Life Care Partnership, 2015; CQC, 2016; DoH, 2013; NHS England, 2014; DoH, 2016; DoH, 2017) and fit with the

Government agenda of Personal Independence Payments (PIP). The 'Welfare Reform Act' (TSO, 2012a) made changes to a number of benefits, including Disability Living Allowance, which became PIP, and introduced the rhetoric of independence, choice and control, as there is the ability to choose the support you receive with the budget you are provided. Gott et al (2008) were critical of the notion of 'control' and found that patients were less concerned with control and more concerned that their financial affairs were in order. Concepts of autonomy and individuality so crucial to the revivalist 'good death', appeared alien to most (Gott et al, 2008). Catt et al (2005) found that patients felt pain control was necessary in a good death, rather than the clarity of thought that is necessary for an individual to exert their choice and control, which would come with fewer opiates.

2.5.5: Choice and policy

What's important to me. A Review of Choice in End of Life Care (The Choice in End of Life Care Programme Board, 2015) and *Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care* (DoH, 2016) are the two documents that have the concept of choice at their heart. 'Our Commitment to you' (DoH) goes as far as saying that choice 'should play the greatest role' in end of life care. Furthermore, that choice is 'inextricably bound up with quality' and that greater 'choice' will enable high-quality services in all settings and will reduce variations in quality of care. 'What's important to me' (2015) reports that during the unpredictable time at the end of life it is 'vital to offer people choice and control over the things that are important to them at this point of maximum vulnerability in their lives'. Choice is also associated with personalised care, such as that described via PIP payments but also through ACP or EPaCCS. As discussed above, policy links ACP and EPaCCS with the fulfilment of wishes regarding preferred place of death, which is implicitly linked with the notion that a patient will choose to die at home and therefore they will have a 'good death' (CQC, 2016). Choice is also linked with the provision of a seamless service as individuals and their families are enabled to 'exercise choices in their end-of-life care, including dying at home or in their care home. Hospital admissions should be avoided where possible, if that is not the wish of the individual' (Neuberger, 2013, p.42). Choice is also described as a right or as a duty to patients (TSO, 2012b; DoH, 2014). Whilst promoting choice, 'Actions for end of life care' (NHS England, 2014) acknowledged that choices will 'fluctuate throughout the course of their illness, and vary from person to person' (p.15). Furthermore, it is recognised that some will want to be in complete control of decisions, whilst 'others will not want, or be able, to take

this on for themselves' (NHS England, 2014). Choice is prized in policy, charity statements and reviews, but is also critiqued as not being a welcome choice for all.

2.5.6: Criticism of choice

Pollock's (2015) review of literature stated that, 'We know little about how patients value choice or, indeed, if they perceive themselves to be exercising choice in relation to their options for death and dying' (p.19). There is also criticism of national campaigns (NCPC, 2014; Macmillan, 2013; Age UK, 2016) which 'promote a good death as an entitlement: a matter of choice and judicious forward planning' (Pollock, 2015, p.19). In reality, patients have a more pragmatic approach whereby it is necessary for them to make a realistic appraisal of the uncertainty of their situation, and the apprehension 'about how they will respond to the unfathomable experience of dying' (Pollock, 2015, p.19). As 'Actions for end of life care' (NHS England, 2014) indicates, some may wish to surrender their 'choice' to others. Furthermore, choice may be viewed as a risk or burden (Pollock, 2015). Applying a blanket policy of 'choice' with a bias towards the choice to die at home risks overlooking older individuals who would rather die in hospital (Catt et al, 2005).

In reality, 'choice' is somewhat of an illusion as healthcare systems will constrain choice. A local example is that an individual may choose to die in a hospice, but if they do not meet the hospice criteria they will not be admitted. Their choices are then limited to home or a nursing home. An individual may not wish to return home for any amount of reasons, which may include lack of family support, fear of lack of community support, difficult housing situation, and so on. In these cases the only option remaining is a nursing home, which constitutes no choice at all. Furthermore, as Gawande (2015) points out, nursing homes do not promote choice of the individuals residing there. There is further loss of choice and control experienced as the nursing home processes and procedures dominate daily life.

Drought & Koenig (2002) propose that the 'choice model manifested in the ethics of end-of-life care is fundamentally flawed' (p.116). Furthermore, the problems discussed above in the policy themes can be traced back directly to the illusion of patient choice (Drought & Koenig, 2002). They state that the notion of choice is wrapped up in the economic and cultural ideology that views individuals as solely responsible for their economic and political power in a culture obsessed with the power to makes decisions that control their lives, and that bioethics ideals have been pushed even further (Drought & Koenig, 2002). These ideals then tie back in with the neoliberal Government agenda seen in the PIP concept; that everything

is for sale and that you have a right to choose. This concept fits badly with the inevitability and reality of death, over which we have no choice or control in the end. As with individual preferences for place of care and death, the choices individuals make are subtle, nuanced and complex. The simplicity of choice equalling good death versus no choice equalling bad death, again does not consider the lived experience of dying. It leads to the marginalisation of groups such as older people and those who care for them as they do not fit into the classical picture of what palliative care is and how that care is delivered (Seymour, 2017).

2.6: The importance of diagnosis

On average, people have 3.5 admissions to hospital in their last year of life, spending almost 30 days in bed in hospital (NICE, 2011). However, the majority of palliative care is accessed by people with cancer (Dixon et al, 2015). Furthermore, as the population ages, the need for palliative care is increasing rapidly, particularly amongst those with non-cancer diagnoses. In a review of the evidence, El-Jawahri et al (2011) found that when palliative care services were involved, patients experienced improved quality of life; furthermore, there was also improvement in family and caregiver outcomes. The number of people aged 85 or over is expected to more than double by 2037 in the UK (Dixon et al, 2015). However, 88% of palliative care patients have cancer, even though cancer accounts for only 29% of those requiring palliative care. Studies have shown that individuals aged over 65 years do not have the same access to palliative care despite having similar needs to those with cancer. Different illness trajectories have been blamed for this failing (Murray et al, 2005). For example, Seymour (2017) reports that fewer than 5% of individuals with diseases other than cancer and with a less certain prognosis received any palliative care input. Figure 9 illustrates this point.

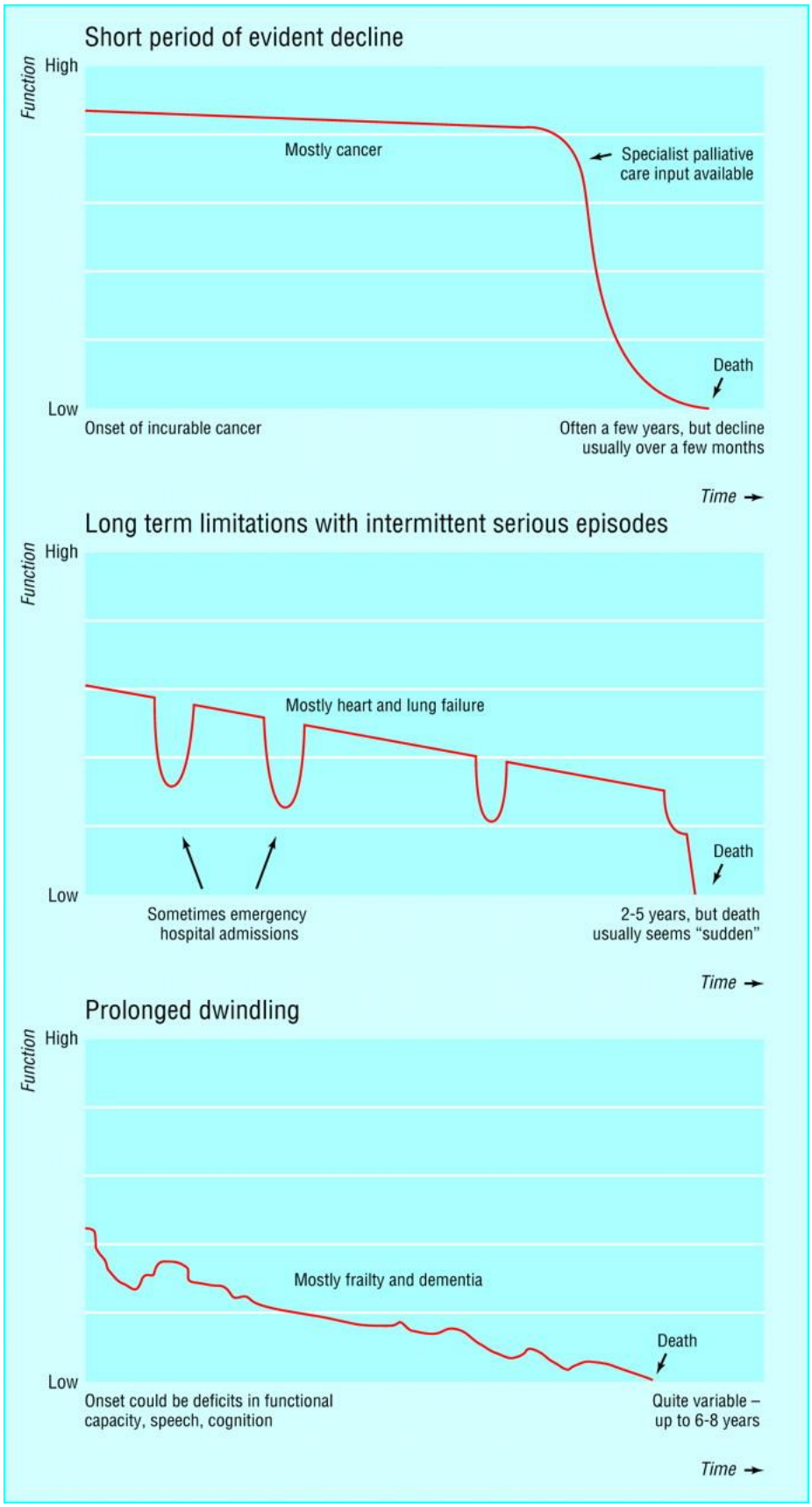


Figure 9: Typical illness trajectories for people with progressive chronic illness (Murray et al, 2005, p.1008)

Figure 9 highlights the three typical illness trajectories for patients with progressive chronic illness: cancer, organ failure and frailty or dementia. Trajectory one is typical of cancer. There is generally time to anticipate palliative needs and plan for end of life care. With the trend towards earlier diagnosis in cancer, and greater openness about discussing prognosis, this trajectory works well with traditional specialist palliative care services, which concentrate on providing comprehensive services in the last weeks or months of life (Murray et al, 2005).

Trajectory two is typical of organ failure such as heart failure and chronic obstructive pulmonary disease. These patients have occasional acute episodes that could result in death. If the patient recovers there is general decline in function over time. The timing of death is uncertain due to the gradual decline in function and the fact that an unexpected exacerbation could be fatal (Murray et al, 2005).

Trajectory three is typical of older age with dementia or Alzheimer's and/or 'generalised frailty of multiple body systems' (Murray, 2005, p.1008). This group is often referred to as 'elderly frail', and Murray et al (2005) refer to it as 'prolonged dwindling'. This trajectory is characterised by progressive deterioration in cognitive and/or physical function. This is accompanied by weight loss and loss of functional capacity. Events such as pneumonia or fractured neck of femur may result in death. Figure 9 illustrates that this is the least clear trajectory and that prognosticating end of life is difficult due to the 'dwindling' and the ability for a medical event that would not be a significant in a young healthy adult to be fatal.

However, the perception of dwindling and the medical definition of frailty in Section 2.2 does not take into account a patient's perspective of the impact of being diagnosed. Frailty has gained prominence since 2002, as illustrated in iterations of *Brocklehurst's Textbook of Geriatric Medicine and Gerontology*; in early editions there was little mention of frailty, then in the 2002 edition it became main focus, with three chapters devoted to it (Pickard, 2013). This coincided with the emergence of geriatric medicine, in tandem with the rise of 'successful ageing' (see Section 5.5.1). Ageing is viewed as a pathology, with over 25% of 85–89 year olds classified as frail (Pickard, 2013). The NHS Long Term Plan (DoH, 2019) addresses the growing demand on the NHS due to ageing population by setting out how older people will be supported to 'age well'. This involves a reorganisation of acute and community services aimed at reducing hospital admission through frailty assessment and same-day discharge, and in the community often through setting up cross-sector frailty teams, which also includes same-day assessment. However, there is no mention of the implication if frailty is viewed as an end of life phase. Therefore, no guidance is given on how frailty and end of

life should be managed and what care an older person might expect at the end of their lives as they 'dwindle'. As a predictor of mortality, Keeble et al (2019a) found that trajectories were better than 'single point in time' measures, but highlight that more research is required.

Assessing frailty in order to manage high health and social care usage means that there is a stigma attached to being labelled as frail. This leads to the dehumanisation of older people living with frailty, emphasising their high use of health and social care services as a 'problem' that needs solving. (This is discussed further in the Chapter 5: Discussion.) The frailty label does not take into account the heterogeneous nature of frailty. Warmoth et al (2016) found that people aged 66–98 'actively resented the identity', even those objectively classified using frailty measurement tools such as Fried et al (2001) and Rockwood (2007). Being diagnosed as frail by others can contribute to a frailty identity that leads to behavioural changes, which include reduced participation in social activities (Warmoth et al, 2016). Bunt et al (2017) and Borgstrom (2016b) highlight the loss of identity and social death that precede actual death for older people living with frailty. As older adults increasingly rely on their informal social relationships and social environment, the concept of social frailty becomes ever more important and is looked at further in the discussion chapter (Chapter 5). Vulnerability is a concept also being looked at as a way to conceptualise older people with a higher level of needs. However, this label is not without its issues. Taylor (2020) points out that the label promotes a deficit mindset, puts disparate groups of people together in one convenient box, and reinforces distinctions between the deserving and underserving, thus changing behaviour toward them. Furthermore, it overlooks the root causes of the vulnerability and indeed the role of health and social care in perpetuating that vulnerability. It presents the older person as a problem that stems from individual 'traits, life choices or misfortune', which brings us back to concepts of successful ageing (discussed in Section 5.5.1) (Taylor, 2020, para 11). However, older people living with frailty *are* vulnerable within a system focused on discharge and that emphasises the expense and burden of caring for them. For example, a diagnosis of frailty rather than cancer means less access to services such as palliative care, which perhaps suggests the diagnosis itself creates vulnerability.

In reviews of end of life care and in charity statements, issues with older people accessing palliative care have been raised (CQC, 2016; Age UK, 2016; Neuberger, 2013). In their grounded theory study 'Are decisions about discharge of elderly hospital patients mainly about freeing blocked beds?', Ekdahl et al (2012) found a core category of 'thinking of

discharge all the time'. They found that rather than fulfilling the needs of patients at hand there was a constant focus on discharging the patient. It was felt that this explained the fast pace on the wards, 'why elderly patients were not invited to participate in medical decision-making process, why the staff did not always feel happy about the decisions they made, and why the patients did not feel welcome in the hospital' (p.6). The study also found discriminatory behaviour where older patients were treated differently to younger patients. The study recommended the elderly were treated in 'age attuned' hospital wards that can cope with the complexity of multiple comorbidities together with shifting social care needs, rather than the 'super-specialised and diagnosis-oriented hospital wards that are particularly common these days' (Ekdahl et al, 2012, p.7). In their study of transitions that older adults make at the end of life, Hanratty et al (2012) highlighted the possibility that 'the health system is structured in such a way to support the delivery of poor care to older people', and that this is worthy of future attention. Seymour (2017) repositions 'end of life care' as 'care of older people' (p.81). Perhaps this way of viewing care of the older people would help with earlier palliative input.

There is little evidence of the experience of this marginalised group and the people who care for them within a 'deeply ageist culture', with policies that do little to allay concerns of being a burden by emphasising the high cost of an ageing society (Lloyd, 2011; Seymour, 2017). However, all too frequently, this group experiences crisis rather than anticipatory care, and a focus on rapid discharge from hospital towards the end of life. The second section of this chapter will now present a literature review on hospital discharge at the end of life.

2.7: Literature review one: Hospital discharge at the end of life

Between 2004 and 2008, 78% of people had at least one hospital admission in the last year of their life (National End of Life Care Intelligence Network, 2012). Therefore, part of the experience for many at the end of life is the discharge from hospital back to the community. This transition in care will often be accompanied by a shift from curative to palliative care. Although, as discussed earlier, there may be no explicit recognition that the patient is at the end of life, but he or she will be transferred to a nursing home as increasing comorbidities and frailty has resulted in the decision being made that a return home is no longer safe. The transition to palliative care combined with the transition from hospital to the community, and potentially a whole new setting such as a nursing home, is a very challenging time. Foremost it is challenging for the patient, but it is also a time of transition for family/carers. The transition from hospital to the community requires input from a wide range of health

and social care professionals based in the hospital and in the community, as well as care agencies or charities such as hospices. Hanratty et al (2012) describe the transition between care settings as a particularly vulnerable point in end of life care delivery. There is also potentially a link between the discharge and whether the individual comes back into hospital soon after returning home. This is therefore an important area to look at.

2.7.1: Search method

This study is guided by constructivist grounded theory methodology, which has also guided the literature review. Thornberg & Charmaz (2012) dismiss the dictum of not reading literature until the end of analysis as per classic grounded theory methodology. On the contrary they say,

> *An early and on-going literature review reveals how the phenomenon has been investigated to date, helps the researcher to be aware of and how to avoid earlier conceptual and methodological pitfalls, and stimulates theoretical sensitivity … Using the literature enriches the analysis, while simultaneously encouraging the researcher to take a crucial stance and challenge 'emergent' concepts and ideas.* (Thornberg & Charmaz, 2012, p.245)

This approach necessitates a critical, reflective stance. The approach also takes into account that there are pragmatic reasons for the researcher to have started reading the literature and theorising when developing a research proposal and the protocol submitted to the ethics committee.

2.7.2: Search strategy

The search method was based on a basic version of the PRISMA model to help reduce bias and increase transparency (Liberati et al, 2009) – see Appendix 2. The aim of the literature review was to find previous studies regarding the processes and perspectives of stakeholders involved in discharge from hospital to the community at the end of life. The following databases were searched: EBSCO, including Abstracts in social gerontology; Academic search complete; Cinhal and Medline; Google Scholar; Pubmed; Scopus and Zetoc. Key search terms and phrases included 'palliative' or 'end of life' together with 'multiple perspectives' or 'interview' and 'discharge' or 'discharge from hospital'. For further details of exact search terms and strategy used for each database see Appendix 2. The Boolean operators 'and' and 'or' were used to combine search terms and phrases. Pertinent

references that were identified from the literature obtained were also retrieved. It was felt to be most relevant to identify more recent perspectives and procedures, so only literature from the last ten years and in English was critically reviewed.

2.7.2.1: Search one results

A thematic analysis was used, as with the policy analysis above. A theme matrix, with the rationale for inclusion in the literature, is included in Appendix 2. The literature review generated data regarding stakeholder perspectives, which included patient perspective and health professional perspective. A search regarding discharge processes found that data on discharge tools was limited. As this search was limited and the data collection setting/participants changed, a second search was carried out that looked more specifically at discharge, end of life, frailty and older people – see Section 2.8.

2.7.3: Stakeholder perspectives

Previous studies into end of life issues or palliative care tend to look at patient and family or health professional perspectives separately, and only one study considered a range of stakeholders perspectives of discharge at the end of life (Hanratty et al, 2014). This mixed-methods study found that in the last year of life transitions between care settings were common, with many moves made shortly before death. The research involved in-depth interviews with family and carers, and telephone interviews with care commissioners and providers using case scenarios derived from the interviews with carers, as well as analysis of statistics. The participants included 30 patients aged over 75 years, in their last year of life, diagnosed with heart failure, lung cancer and stroke; 118 caregivers of deceased aged 66–98 years, who had died with heart failure, lung cancer, stroke, chronic obstructive pulmonary disease or selected other cancers; and 43 providers and commissioners of services in primary care, hospital, hospice, social care and ambulance services (Hanratty et al, 2014). The study found the experiences of transitions that patients and carers experienced were disjointed and that organisational processes were prioritised over individual needs. It was also found that the family carer was excluded from participation in institutional care but at home was the co-ordinator and provider of care. Family carers were also lacking the information and support to extend their role with confidence. The contributors to unnecessary transitions were seen to be out-of-hours services and care homes. Families found that one of the most important influences on the transition was a good relationship and communication between professionals in different settings and sectors; however, this was rarely acknowledged by

staff. As my study focuses on the views of a range of stakeholders involved in discharge it will be possible to gain more detailed understanding of the relationships and communications between stakeholders and settings. My study also took place after the Liverpool Care Pathway was removed from use at the end of life. It also differs from Hanratty et al (2012) as it is about the experience and perceptions of stakeholders regarding the discharge of an older person living with frailty who is considered to be approaching the end of life, whereas their focus was of three specific conditions: heart failure, lung cancer and stroke.

2.7.4: Patient perspective

Hanratty et al (2012) carried out a study regarding the experiences of older adults who were transitioning between care settings at the end of life. The Framework Analysis of the patients' perspectives showed communication to be major theme. Hanratty et al (2012) drew attention to the fact the patient experienced some good communication, but that there was also poor communication leading to the patient feeling they were not listened to. Equally, carers did not feel heard, particularly when advocating for the patient. This ties in with other research into patient experience of discharge at the end of life, which found communication with the patient to be an issue (Marston et al, 2015; Benzar et al, 2011). Marston et al (2015) found that patients struggled living with an uncertain prognosis and were less likely to cope after discharge with poor information from health professionals. Communication across services and between professionals was also found to be key to successful discharge, for example, role confusion and confusion about who to call when things were not going well reduced how well patients coped in the community once discharged (Benzar et al, 2011; Marston et al, 2015). Tied into communication between professionals and services is the theme of planning and coordination. This was found to be an important aspect of ensuring that discharge and immediately after went well (Hanratty et al, 2012; Benzar et al, 2011; Marston et al, 2015; Manson et al, 2017). There is a need for clinicians to understand each other's roles and to communicate effectively with patients. Marston et al (2015) suggest an individualised discharge sheet so that patient and caregivers know who to contact and in order to establish an interface between hospital and the community. However, Benzar et al (2011) reported limitations of discharge summaries, since issues may arise in the community that were not anticipated in hospital. Adam (2000) found the information, practical advice and support carers received in hospital facilitated them in caring at home following the terminally ill patient's discharge from hospital.

Support in the community once discharged is also a concern for patients. Manson et al (2017) studied the perspectives of patients with malignant spinal cord compression due to metastatic cancer. This study did not report whether the participants were considered end of life or not, but it has been included because it can be assumed that the patients are living with a very life-limiting condition. This study found that lack of communication between services resulted in patients feeling frustrated when they were not supported adequately in the community, either through symptom management or equipment provision. Common themes found in the papers include: unmet physical and psychological needs; lack of communication between professionals and services; role and service confusion; the need for greater follow up once discharged; and collaboration between services being key to improving patient experience and care.

2.7.5: Health professional perspective

Studies relating specifically to health professionals' perspectives of discharge from hospital at the end of life were limited. Many studies were related to advance care planning or discharge in general. Although based in Singapore, the findings of Tan et al (2015) are applicable to healthcare in the UK and met the inclusion criteria of being in English, within the last 10 years and regarding discharge from hospital at the end of life. Registered nurses were interviewed about 'rapid discharge' of patients with cancer who wish to go home to die. The study found that the actual and preferred locations of care and death are often different, and that there was a benefit of early palliative care to assist 'more successful transitions to the end of life' (p.2607). However, they found that there was a reluctance of patients and healthcare professionals to engage in discussions about end of life matters, which did not help when there was a complex rapid discharge case. The study surmises that early and ongoing end of life discussions, together with the initiation of an end of life discharge framework and early community liaison, can facilitate better quality rapid discharge and therefore reduce stress for patients, families and health professionals. These findings were backed up in a subsequent study which was an audit of the rapid discharge framework (Tan et al, 2016).

Coombs et al (2015) looked at doctors' and nurses' views of the experience of transferring patients from critical care to home in order to die. Focus groups with critical care doctors and nurses found that whilst there were positive views about transferring critical care patients home to die it rarely happened. The barriers identified as preventing patients being discharged to die at home included: decisions needing to be made quickly due to the

impending death (hours or days); staff views and knowledge of community-based skills and resources; and staff perceptions of a family's ability to cope with a death at home. Again, early discussions are recommended, this time with family as they will be taking on a significant caring and coordination role for someone who is expected to die within hours or days. Successful transfers also required a reduction in the knowledge gap around community services and 'internal discharge processes for patients where the outcome of transfer to the community is death, not recovery or rehabilitation' (Coombs et al, 2015, p.360). The authors are critical of the fact that there is no literature that reports on the experiences of community teams when receiving a patient home to die from critical care. Development of integrated policy and procedure to guide primary and secondary teams is hindered by this lack of knowledge and fails to identify the level of support needed by patients and their family members who would like the patient to return home to die.

2.7.6: Discharge tools

There is also little research or data collection regarding the processes that facilitate discharge at the end of life, such as Fast Track (Johnston et al, 2014). Fast Track is a tool used by an appropriate clinician to outline the reasons for a 'fast track decision' on whether the patient's care will be funded by the NHS post discharge. The document is submitted to NHS Continuing Healthcare to assess whether funding will be provided or not. If it is not, then Social Services funds the patient's agency or nursing home care or it is privately funded following a means test. Johnston et al (2014) stated that a process such as Fast Track has the potential to arrange a funded package of health and social care quickly at the end of life, which in turn can help an individual to achieve their preferred place of care and readmissions can be reduced, which has a positive effect on hospital beds and cost savings. However, it highlighted that Fast Track also has challenges that lead to poor care, delayed discharge, lack of continuity of care and readmission to hospital, causing patients and family anxiety and causing extra strain on the NHS. In summary, there is limited research regarding discharge tools and facilitation, such as Fast Track, and very little investigation into the experience of stakeholders involved in the discharge of someone in the last weeks or months of life. Care of individuals at the end of life is a key area of interest in current policy, as is the need to work in a more integrated way and to save money.

The literature search found one audit that evaluated the Fast Track discharge service for patients wishing to die at home (Moback et al, 2011). The audit found that the main barriers to enabling patients to die at home were: difficulty with timely dispensing of drugs and

provision of equipment; transport issues; families needing more than 72 hours to adjust to the patient coming home; and unexpected deterioration in condition.

2.8: Literature review two: discharge from hospital of older people living with frailty, discharge at the end of life

A second literature search was carried out after data collection was completed because the participants and settings were slightly different than was planned at the beginning of the study.

2.8.1: Search strategy

The new search aimed to identify studies that have looked at the discharge from hospital of older people living with frailty who were nearing the end of life. Search criteria included 'hospital discharge' or 'patient discharge', 'end of life' or 'terminal' or 'dying', 'frail' or 'elderly' or 'aged' or 'geriatric'. It was hoped that these terms would cover all aspects of the search that may feature in American searches as well as British. Advice was sought from the school librarian, who specialises in health research literature searches. He recommended using Google to narrow the search. Ideally, studies would have included stakeholder views. Studies were excluded if they were about interventions, treatment evaluations, assessment or screening tool evaluations, medications, randomised control trials, intensive care, trauma patients and end of life with no frailty. See Appendix 3 for the search matrix and flow chart. Once again, thematic analysis was used.

2.8.2: Search results

The search was quite specific and consequently, even though well over a thousand studies were reviewed, only four were selected to add to the search already completed. I used Twitter to ask authors prominent in the field if they knew of any studies and a further four were found to be appropriate for this synthesis.

Whilst the search was to look for evidence related to frailty or very old age, discharge from hospital and end of life, there were no studies that encompassed all three areas and included stakeholder views. Consequently, studies were included that were relevant but not necessarily encompassing all aspects of the search. A combination of the studies has been used to gain greater understanding of the previously researched issues and context around the discharge of older people living with frailty who are approaching the end of life and are being discharged from hospital. Appendix 3 comprises a matrix showing the rationale for

inclusion of studies in the second literature review. Two book chapters were also used, which complemented the literature search. These were 'Social Policy and Care of Older people at the End of Life' (Ellis et al, 2016) and 'National end of life care policy in the English context: the problem and solution to death and dying' (Borgstrom, 2016a). Three themes were identified from the second literature search: medicalisation of ageing and death; the importance of carer involvement; and the need for coordination of care.

2.8.2.1: Medicalisation of ageing and death

Huijberts et al (2015) conducted a cohort study that included frailty as well as cancer and end stage organ failure. It looked at end of life care during and after hospital admission. It found that patients with cancer had their end of life care needs better identified and had the highest rates of healthcare utilisation. This finding is supported by Ellis et al (2016) who discuss the oncology-centric model of palliative care as being 'inappropriate and inaccessible to older people with multiple conditions and complex, chronic disease trajectories' (Ellis et al, 2016, p.17). Geriatric conditions in all three patient groups were associated with institutionalisation, quality of life and mortality (Huijberts et al, 2015). Three-quarters of the patients with frailty and end stage organ failure died within three months of discharge, with end of life care often arranged at the time of the hospital discharge. The difficulty of prognostication is discussed and it is suggested that hospitalisation is a good time for patient and doctor to reassess the situation and to think about future wishes regarding end of life. Advance care planning of this nature was found to help reduced readmission and 'undesired care transitions'. Over a third of deceased frail patients were hospitalised in the last month before death. This study discussed advance care planning in terms of importance of desired care options, preferred outcomes, decreasing undesired care transitions and reducing carer burden. However, it does not address preferences regarding place of death, which as Gott et al (2004) found may involve a transition back to hospital. This is discussed in more detail below.

Ellis et al (2016) also consider the reasons for older people's lack of access to palliative care and relate it to issues of medicalisation and prognostication of frailty. They suggest that becoming frail results in older people 'inhabiting a space between living and dying', whilst current policy and practice 'fails to acknowledge dying as a normal part of the life course' (Ellis, 2016, p.18). The medicalisation of frailty then creates issues that shape the dying experiences of older people and means that dying is no longer recognised as normal part of ageing. Medicine's reframing of ageing and dying as processes that should be delayed and

controlled have disrupted the predictable relationship between life and death. Borgstrom (2016a) also highlighted that policy discourses are framing death and dying as something that can be managed within a medical system. Prognostication, as discussed above, is difficult due to the 'dwindling' end of life trajectory of older people living with frailty. This in turn affects the ability of the individual to access end of life care that is dependent on the ability to identify when someone is entering the terminal phase. Ellis et al (2016) suggest it would be more beneficial if end of life care were not based on knowing when someone will die. Ellis et al (2016) report that older people are least likely to die at home and less likely to receive hospice in-patient services.

However, dying at home is not a simple concept, as shown by Gott et al (2004, 2017a). The concept of 'home' with regards to location of dying, cannot be unproblematically translated into physical location because the concept has multiple meanings. The decision making that informs patient preferences can depend on 'concerns about the quality of care received at home and, most crucially, fears of being a "burden" to informal carers, particularly where it is perceived that the carer's health is threatened or values relating to physical intimacy with children are transgressed' (Gott et al, 2004, p.465). The study concluded that there is a complexity to the preferences for setting of care and dying. It found that whilst, as per policy, older people do want 'choice and control', these choices contradict the assumption that a medicalised, institutional death cannot be a 'good death'. For example, transfer back to hospital may be what the patient wishes as their health deteriorates, particularly if their social network and community care not sufficient. In 2017 Gott et al (2017a) conducted further research regarding the end of life care preferences among people of 'advanced age'. It compared the preferences of Maori people aged over 85 and non-Maori people aged 80–90. The theme of being a burden once again arose and was the top priority of both Maori and non-Maori people. This preference is set in the context of pervasive ageism and the low societal value placed on old age. Again, the preferences of older people are at odds with the Western individualistic model of palliative care policy and practice, and a relational model based on social connectedness and 'total care' of a person is proposed. A home death did not feature in the top three end of life care priorities for either group, and a 'good death' was associated with pain and symptom control, attending to spiritual concerns and 'getting affairs in order' (Gott, 2017a, p.7). The study also highlighted the gendered differences between the preferences of males and females, with non-Maori men expressing a desire for life-sustaining treatments. The study called for further research into the ways in which cultural identity, ageism and gender shape end of life care preferences, in order to achieve

the goal of meeting end of life preferences for all people of advanced age. The increasing number of older people that are living alone and in isolation poses a challenge for policymakers advocating a home death as an aspiration, as there is a reliance on informal carers to achieve this goal.

2.8.2.2: The importance of carer involvement

The importance of carer involvement and empowerment was found to be important, not only for the discharge process but for reducing carer strain and hospital readmissions (Bauer et al, 2009; Baillie et al, 2014). Ellis et al (2016) discussed the highly complex relationship older people have with their families, which runs counter to the 'individualistic nature of current policy'. The relational and interdependent nature of death and dying are seen as inferior or less important than an 'autonomous individual'. Borgstrom (2016a) also proposes a relational way of envisioning care, considering that the growing number of home deaths are largely supported by family and friends providing care. Ewing et al (2018) found that an organisational, rather than relational, focus on patients' needs was creating a barrier to supporting carers during hospital discharge. Furthermore, the study found that although carers were keen for the patient to go home, they were unaware of the reality of 24 hour-a-day caregiving and that carers were not given the level of detail needed to educate them. In addition, carers were unaware of the lack of support available in the community, particularly at night. The study also found that health professionals found it hard to discuss end of life issues with carers who were unaware that the patient was approaching end of life. The study concluded that discharge planning that included the carer, and educated them, could potentially prevent breakdown of care at home and subsequent readmission to hospital. This study highlighted how the relationality of carers' needs was also important, not only the patient. Early involvement of the informal carers in the discharge process enabled problems to come to light earlier, thus smoothing the transition (Popejoy, 2011). Shared decision making, education of the informal carer, and therefore their empowerment, were recommended by Bauer et al (2009), Baillie et al (2014) and Hestevik et al (2019). However, whilst Baillie et al (2014) felt that nurses were well placed to empower informal carers, they were disempowered to do so by the system push to discharge quickly in order to increase hospital capacity. Bauer et al (2009) also recommended that the identification of 'special needs' of older people living with frailty was important, but reported that this was not happening in their study. Regarding the complex needs of older people living with frailty, Hestevik et al (2019) raised issues regarding the coordination of the 'multifaceted

arrangement of multiple service providers' that are needed to facilitate discharge and for the older person to remain at home (p.10).

2.8.2.3: The need for coordination of care

Access to care and dying at home are considered by Ellis et al (2016), who describe applying for and accessing care from the UK health and social care system as 'fraught with complexity'. They quote Humphries, who states that the system is, '…criss-crossed with fault lines in how services are funded, commissioned, provided and regulated – between NHS and local authority social care, private and public funding, and private and public delivery' (2013, p.8).

This results in poorly integrated care for older people living with frailty, who have 'fallen through the cracks' in a mixed-market approach. Hestevik et al (2019) concluded that a redefining and reorganisation of organisational structures may need to occur in order to ensure continuity of care and the wellbeing of older people being discharged from hospital. This would also have benefits in terms of their other finding, that communication needed to be improved not just with patients and their carers but between the hospital and social care providers to improve the coordination of care and to facilitate recovery at home. Issues of interprofessional working were also raised by Bauer et al (2009), who recommended effective interdisciplinary communication by health professionals as a factor that can improve the discharge planning of older people living with frailty. Baillie et al (2014) also discussed silo working creating a barrier to discharge and proposed that a vertically integrated organisation, without the transitional divide between hospital and community, could resolve communication issues. They found that older people with frailty did not fit the hospital goal of 'cure', and that services need to adapt to better meet the current and future population's needs. The transition from hospital to home setting was also found to be facilitated by preparation of the home environment, coordination of care, and assessment of post-discharge needs (Hestevik et al, 2019). Bauer et al (2009) also found that ongoing support after discharge improved the hospital discharge for older people living with frailty.

2.8.3: Summary

In summary, whilst the literature regarding the intersection of hospital discharge, older people and end of life is limited, there were clear themes. Firstly, access to palliative care for older people with frailty is prevented owing to a system that medicalises frailty and death and relies on prognostication of the terminal phase, which is difficult with a 'dwindling'

condition. Secondly, the oversimplification of the concept of preferred place of death decisions is at odds with the policy push for death at home, when there is a difference between policy concept of good death and an older person's concept of a good death. The literature suggests a relational model verses a Western individualistic model that prizes independence, autonomy and choice. Thirdly, the literature shows that informal carers are important for enabling discharge and community care and that adequate involvement of the older person as well as their carer facilitates discharge, and reduces carer burden and burn out, as well as readmission rates. Empowerment and education of patient and family are important but it can be difficult for health professionals to achieve when they themselves are disempowered by the system push to discharge and lack of resources. Finally, coordination of care across health and social care is important to prevent older people from 'falling through the cracks'. Integrated care also helps to prevent silo working and improves multidisciplinary communication.

2.9: Conclusion

This chapter has looked at the evolving end of life care policy rhetoric over the past 15 years, and presented a review of the literature around hospital discharge at the end of life, and latterly, hospital discharge at the end of life for older people living with frailty.

Themes of variations of access to and quality of care provision are constant, as are ideas on how these issues will be resolved through improving access, development of professional knowledge, technology integration, communication, seamless services whilst transitioning from hospital to community, and from healthcare in hospital to either health or social care in the community. However, in the intervening years since the *End of Life Care Strategy* (DoH, 2008) these issues have not been resolved. In the context of these unresolved issues around end of life care, discharge is an important area to examine as it has such a large impact on the patient's life and well-being. It may also influence whether the patient returns to hospital again in a short space of time. When frailty was included in the search there was even less evidence. However, the second search shone a light on the need for carer involvement, the medicalisation of ageing and death and how this is detrimental to the patient, and that older people living with frailty are at risk of 'falling through the cracks' between health and social care services.

An examination of the current literature regarding discharge from hospital at the end of life showed limited involvement of all stakeholders. My study sought to include all the key

individuals directly involved in the process of discharge to the community for older people living with frailty, considered to be in the last months of life. The study used an approach whereby a range of stakeholders were given the opportunity to discuss their experience of the discharge process. The study aimed to discover and explain common themes on specific cases as well as across the cases. The study endeavoured to not only highlight areas for improvement, but also areas of good practice. Recommendations will help to improve efficiency and free up beds whilst improving quality of life for future patients and their families, making a valuable contribution to the knowledge in the areas of frailty, palliative or end of life care, hospital discharge, and multidisciplinary working across health and social care, in the hospital and the community. The next chapter will present the underpinning methodology, research design and methods of the study.

Chapter 3: Research Methodology and Methods

3.1: Introduction

This chapter provides an overview of the methodology and the methods employed for this research study. The chapter begins by revisiting the aims of the study. There then follows a summary of the chosen research methodology, a qualitative approach using a constructivist grounded theory perspective. The antecedents of grounded theory and its philosophical underpinnings are also presented. Emphasis is placed on why constructivist grounded theory was chosen as the methodological framework for the facilitation of inquiry. The chapter also details the process of data collection and analysis, and a discussion around issues of ethics and rigour.

3.2: Overall aim of the study

This study was designed to explore the perceptions and experiences of stakeholders involved in the discharge from community hospital of an older person living with frailty approaching the end of life. This included the patient, their informal carer(s), the hospital and community health professionals.

3.3: Research methodology

This section will discuss the methodology underpinning the study. It provides an introduction to Grounded Theory and the developments in Grounded Theory. This leads on to a discussion and analysis of social constructionism and constructionist grounded theory as the overarching paradigm for the study.

3.3.1: Methodological choice

> *The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. The major transition to the end of life period is in changing the focus on the person from curative and restorative care, which aims to extend the quantity of life, to palliative care which aims to improve the quality of life.* (New Zealand Ministry of Health, 2015, p.4)

The New Zealand definition of end of life care echoes that of the Gold Standard Framework (National Gold Standards Framework Centre, 2011) and emphasises the transition from curative to palliative care. During discharge there is also a transition in place of care and care

provider, and potentially a completely new setting, for example, nursing home. Furthermore, the care provision systems themselves are in a state of flux. It is because of the complexity of the issues surrounding the discharge back to the community at end of life, and due to the lack of research in this area that grounded theory has been selected as the methodology.

Grounded theory is appropriate when little is known about the area of study and there is a focus on how individuals interact with the phenomenon under study (Urquhart, 2013). Furthermore, close attention was paid to what people were saying, which lead to new concepts, new theories and innovation. As Clarke et al 2015 stated, 'Grounded theory is a useful methodology for the study of interpersonal activities between nurses, patients and others. It is particularly useful when little prior research has been undertaken in a specific area of enquiry' (p.16). Grounded theory also provides a helpful framework for guiding data collection and analysis, which will be discussed further below.

3.3.2: Grounded theory

Awareness of Dying was published in 1965 by Barney Glaser and Anselm Strauss, and is considered to be the inception of the grounded theory methodology. In 1967 they published *The Discovery of Grounded Theory: Strategies for Qualitative Research*, describing the new research process and providing founding principles and guidelines for the grounded theory process. It is worth noting the context and circumstances within which 'Awareness of Dying' was created. It could be said that the early 1960s were a time when health professionals did not share a great deal of information with patients regarding their prognosis. The study was foreshadowed by personal experiences of Glaser and Strauss. Five years before the study began Strauss's mother died and then a friend two years later. The personal experiences brought to his attention to the problems and consequences of lingering deaths as compared with speedy deaths (1965, p.286). This led to a study focusing on the uncertainty of the timing of dying, the awareness of these expectations, how the staff managed, and how the hospital organisation impinged on the dying of patients. After six months, the project was funded and Glaser joined. Glaser's father had recently died and he was interested in death expectations, who was aware of them, how family members affected had discussed his father's illness, how family were handled by doctors, and how everyone treated his father. Together they formulated the paradigm for the study of 'awareness contexts' and a concern with death expectations awareness guided preliminary data collection (Glaser & Strauss, 1965).

For six years Glaser and Strauss conducted intensive fieldwork involving a combination of observations and interviews at six hospitals. The purpose of their research was to contribute toward creating end of life care that was more rational and compassionate (Andrews, 2015). Glaser and Strauss were allowed to observe different aspects of dying: death was 'sometimes speedy, sometimes slow; sometimes expected, sometimes unexpected; sometimes anticipated by the patients, sometimes unanticipated' (Glaser et al, 1965, p.118). They observed nurses and physicians at work, sitting at the nurses' stations, attended staff meetings and talked with patients. They also asked questions and interviewed staff. The theory that emerged presented an eye-opening view of how patient care was affected by the awareness level of the dying process by nurses, physicians and patients (Andrews, 2015).

During their observations, Glaser and Strauss found that Americans in the early 1960s hesitated to talk openly about dying and were likely to avoid telling a person that he or she was dying. As grounded theories uncover previously unknown processes, Glaser and Strauss were able to identify previously unknown levels of awareness of impending death and the effects these levels have on patients, relatives, nurses and physicians. What emerged during their investigation was four distinctly different awareness contexts: closed awareness, suspected awareness, mutual pretence awareness and open awareness.

The 'Discovery of Grounded Theory' (1967), which described the new research method, indicated assumptions inherent in the original, traditional or 'classic' method:

1. There are happenings that can be objectively observed.
2. These happenings occur in predictable patterns that can be conceptualised.
3. Grounded theory seeks to understand processes from participants' perspectives – from their words and behaviour.
4. Grounded theories are dynamic in that they consist of a set of interrelated tentative hypotheses that are modified as new facts emerge. (Andrews, 2015, para. 12)

Thus, a grounded theory that is built upon these underlying assumptions should endure over time, since subsequent research serves to enrich rather than refute classic theories. There is a place for this study to build on the work done so far by building on the work done by Glaser and Strauss and looking at the phenomenon of discharge from hospital at the end of life. However, points one and two (above) indicate the positivist origins of early or 'classic' grounded theory. The issues with the positivist approach are discussed further in the next section.

The timing of *Awareness of Dying* is important to note. As discussed in Chapter 2 (Section 2.3.2), palliative medicine and the modern hospice movement developed in the UK from the late 1960s onwards, after 'Awareness of Dying' was published. St Christopher's Hospice, Sydenham, founded by Dame Cicely Saunders, opened in 1967 as the first modern hospice, which combined palliative medicine with clinical research and teaching. Glaser was struck by the 'nothing more to do' phase of his father's dying, which was something Dame Cicely Saunders recognised as an inadequacy of the care of the dying that was offered in hospitals (Glaser and Strauss, 1965). She is quoted as saying, 'there is so much more to be done' (St Christopher's, 2017). She pioneered research on the use of morphine as an effective drug for pain control, along with other detailed studies of new approaches to symptom control. However, Dame Cicely understood that a dying person is more than a patient with symptoms to be controlled and became convinced of the importance of combining excellent medical and nursing care with holistic support that recognised practical, emotional, social and spiritual needs. She saw the dying person and the family as the unit of care and developed bereavement services at St Christopher's Hospice to extend support beyond the death of the patient. Anselm Strauss visited Dame Cicely in the autumn of 1965 (Clark, 2014). Times were changing and both were at the forefront of this new way of thinking about palliative care that has continued through to current times.

Fifty years after it was first published, 'Awareness of Dying' continues to reflect an important process within the healthcare system and to offer relevant implications for improving the quality of end of life care. The research remains relevant, since closed awareness may occur, but it is no longer the norm or expected. Open awareness of dying remains desirable as it enables end of life planning to proceed and offers some control over the manner and timing of death (Seale et al, 1997). It also enables individuals to exercise some control over their last months and days of life. The awareness of dying theory sensitises healthcare professionals to universal problems that surround end of life care and provides them with a means of improving the situation. By applying elements of the theory, physicians and nurses are better able to deal with patients and families during the sudden transition from one type of awareness to another. The theory exposes how the context of patients', physicians' and nurses' awareness can determine how patients experience their last days (Andrews, 2012). While *Awareness of Dying* and *The Discovery of Grounded Theory* are the original and seminal grounded theory texts, they came with a distinct set of philosophical assumptions that will now be explored.

3.3.3: Overview of traditional grounded theory

The epistemological underpinnings of grounded theory are conflicting, owing to the backgrounds and personal epistemologies of Glaser and Strauss. Strauss is cited widely as influencing grounded theory as he was educated at the University of Chicago sociology department (Weiner,2000; MacDonald & Schreiber, 2001). The Chicago School is a name given to an approach to sociological work and is associated with this department. It was formed in 1892 and provides a way of thinking about qualitative research and rigorous data analysis and relied heavily on symbolic interactionism. Symbolic interactionism (SI) is a branch of interpretivism with an emphasis on eliciting and understanding the way meaning is derived in social situations that 'explores the processes of interaction between people's social roles and behaviours' (Blumer, 1969, p.3).

Herbert Blumer (1969, p.3) is seen as the founding father of symbolic interactionism and suggested that the symbolic interactionist position premise is based on the following:

1. Human beings act towards things on the basis of meaning that things have for them.
2. The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.
3. These meanings are handled in, and modified though, an interpretive process used by the person dealing with the things he encounters.

One can see how this could be seen as the major influence on grounded theory. However, Glaser (2005) disputed this fact when he said,

> *The Strauss origination of grounded theory using situational analysis has a pretty heavy impact and dominance, which […] is hard to resist, but grounded theory is just not a situational analysis in possession. But I, Barney G. Glaser, was co originator, if not the originator of grounded theory. I was clear in Discovery of Grounded Theory, Theoretical Sensitivity and Doing Grounded Theory that grounded theory was 'based in a concept-indicator model' leading to conceptualization (p.62) taken from psychological research and used extensively in quantitative research. I then added the constant comparative method – comparing the indicators – to conceptualize the categories and their properties. And I then added Lazarsfeld's notion of the interchangeability of indicators, which led to theoretical saturation, so no more indicators need be attended. Thus grounded theory came straight from survey*

> *research analysis. And it came from Robert K. Merton's training his students in substantive and theoretical coding – conceptualization.* (Glaser, 2005, para. 11)

Glaser was of the view that grounded theory is a 'general inductive method that conceptualises into a generated theory' and that the takeover of symbolic interactionism will remodel grounded theory with negative consequences such as the limitation of the type of data collection resulting in a lack of openness, sensitivity and theoretical concepts (Glaser, 2005, para. 12).

Ultimately Glaser and Strauss went their separate ways and pursued their versions of grounded theory. Glaser's *Theoretical Sensitivity* (1978) introduced concepts of theoretical sensitivity, which means understanding theories and how they are constructed without imposing those concepts on the emergent theory. He also introduced the notion of 'coding families' to help when relating concepts in the data (Urquhart, 2013). However, the insistence of no literature review prior to data collection and analysis is largely unchanged.

Strauss worked with Juliet Corbin, producing *Basics of Qualitative Research* in 1990, which prompted a long and bitter row between Strauss and Glaser (Urquhart, 2013). At this point two strands of grounded theory became identifiable and persist to this day. Strauss and Corbin (1990) provided the clearest signposting of procedures, which could be used as an introduction and instruction manual for grounded theory at students' request. Glaser responded with *Emergence vs Forcing: Basics of Grounded Theory Analysis* (1992) in which he felt strongly that Strauss and Corbin (1998) were being too restrictive in their presentation of grounded theory and that the procedures outlined would limit emergent concepts, instead of forcing them into a preconceived mould. There were two fundamental issues in dispute: 1. The breaking down of the coding process into four prescriptive steps, where Glaser uses three. 2: The use of a coding paradigm and the 'conditional matrix' that were designed to assist with conceptualisation, which again Glaser felt forced coding and ignored the emergent nature of grounded theory. Glaser (1978) suggested 18 coding families. However, in subsequent issues of *Basics of Qualitative Research* Glaser modified his stance on the use of a paradigm to become a perspective or analytical stance helping to systematically gather data (1998). He then further modified his position in 2008 to emphasise researchers making use of a broad range of procedures and analytical tools that suit them. Discussed below is the use of analytical tools, and in the 'Methods' section (Section 3.6) there is a detailed account of the coding process used.

Despite this divergence, there are basic concepts that underpin all grounded theory studies. Charmaz (1995, 2002) identified a number of features that all grounded theories have:

- simultaneous collection and analysis of data (constant comparison)
- creation of analytic codes and categories developed from data and not by pre-existing conceptualisations (theoretical sensitivity)
- discovery of basic social processes in the data
- inductive construction of abstract categories
- theoretical sampling to refine categories (ongoing analysis informs the direction of the next interview or group of interviews and is explicitly aimed at developing theory)
- writing analytical memos as the stage between coding and writing
- the integration of categories into a theoretical framework.

It is important that the theory is grounded in the data and not predetermined by a theoretical perspective. Description should be thick, providing a clear portrayal of the situation that is empathic and understanding of the insider's point of view. Analysis of the data explores and uncovers the meanings participants give to their ideas, feelings, experiences and perceptions.

3.3.4: Critique of traditional grounded theory

The conflict between Glaser and Strauss leads to confusion, particularly for the novice researcher, and ultimately leads to branches in grounded theory. These branches stem from the inadequacies perceived in the grounded theory methods. Glaser insists on a 'classic' or Glaserian grounded theory that is close to the original, since, as quoted above, all other forms erode its ability to identify emergent themes and the full range of possible theoretical concepts. However, Stuassian researchers take issue with the reliance on pure induction, labelling it as naïve and positivistic (Thornberg, 2012). Critics of Straussian grounded theory point out that in his work with Corbin (Strauss & Corbin, 1990; 1998) there is an indecisiveness between positivism and constructivism, but that there is also an acknowledgement that it is not possible to be free of bias. Mills et al (2006) assert that this shows a struggle to move with the 'changing moments of qualitative research' (p.4).

In order to 'reclaim the grounded theory tools from positivist underpinnings' (Clarke, 2005, quoted in Richardson & Kramer, 2006, p.498) a revised, more open-ended practice of grounded theory has evolved that stresses its emergent and constructionist elements. For example, another criticism is Glaser's (1992, 1998, 2005) position that the researcher is unbiased and that the data will 'speak for itself', as well as his disinterest in epistemology. Thornberg (2012) proposes that this is a positivist stance that fails to take into account the influence of the researcher during the research. In contrast, a later version of grounded theory, called constructivist grounded theory, 'assumes that neither data nor theories are discovered, but are constructed by the researcher as a result of his or her interactions with the field and its participants' (Thornberg, 2012, p.248). This version of grounded theory takes into account the way in which the researcher colours the findings, owing to their perspectives, values, privileges, interactions and geographical location. This is a position between realist and postmodern ground that assumes 'obdurate reality' (Blumer, 1969, quoted in Thornberg, 2012) whilst at the same time assuming that multiple realities and perspectives exist (Thornberg, 2012).

Constructivist grounded theory also deals with another criticism levelled at Glaser (1998) regarding his stance on engagement with literature before research. He argues that the literature review should be delayed until the end of the study, or until data collection has started (2005), since one cannot know which literature is relevant prior to the study starting. However, Charmaz (2014) points out that people often research within their chosen field or have worked up a study proposal for funding purposes and will therefore know about it before commencing the research. Furthermore, in order to ensure the study contributes to existing knowledge and to enhance theoretical sensitivity, the researcher should investigate the prior knowledge in the substantive field (Charmaz, 2014; Thornberg, 2012). As the study progresses the researcher is able to carry out an ongoing literature review guided by the codes and concepts that develop, adding to the notion of 'theoretical sampling' proposed by Glaser and Strauss (1967). Theoretical sampling is defined as 'the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data then decides what data to collect next and where to find them, in order to develop his theory as it emerges' (Glaser & Strauss, 1967, p.45).

According to Charmaz (2014), critics during the 1990s viewed grounded theory as 'clinging to an outdated modernist epistemology' that fragmented the participant's story, relied on the authoritative voice of the researcher and accepted empirical truths. However, she

counters that researchers can use grounded theory strategies that start with the assumption that 'social reality is multiple, processual, and constructed' and that the researcher can take into account their position, privilege and perspective as an inherent part of the research reality (Charmaz, 2014, p.13). In addition, she asserts that the research is also a construction, not discovered. In taking this approach, Charmaz has introduced social constructionism concepts, which enable the development of the grounded theory method.

3.3.5: An Overview of social constructionism

Whist social constructionism cannot be traced back to a single source, it is thought to have emerged forty years ago with the publication of *The Social Construction of Reality* by Berger and Luckmann in 1966 (Burr, 2003; Andrews, 2012). Social constructionism has been adopted in psychology and social psychology, 'generating radically different accounts of phenomena' (Burr, 2003, p.3). It is a theoretical perspective, which assumes that people create social realities through individual and collective actions and, like Straussian grounded theory, is rooted in symbolic interactionism. It is a critical stance against taken-for-granted ways of understanding the world. It is in opposition to the positivism and empiricism in traditional science and the notion that the world will unproblematically yield its nature to us through objective and unbiased observation. It acknowledges that common understandings of the world are historically and culturally specific and are products of, and particular to, that culture at a specific time. Furthermore, it posits that our understanding of the world is not derived from the nature of the world but is constructed through daily interaction between people in the course of social life. Therefore, social interaction, particularly language, is of great interest to social constructionists who believe that currently accepted ways of understanding the world are not objective and observable, but the product of social processes and interactions. There is a recognition that descriptions or constructions of social action are bound up with power relations that are prevalent in the current discourse (Burr, 2003).

There are two broad forms of social constructionist theory and research, which focus on microstructures of language or macro linguistic and social structures. Micro social constructionism takes place within everyday discourse. From this perspective, there are multiple versions of the world available and there is no claim of a 'real' world beyond our description. Macro constructionism recognises the constructive power of language. It is derived from/related to social structure, social relations and institutionalised practices. These versions of social constructionism are not mutually exclusive and Burr (2003) pointed

out that a synthesis of the two versions of discourse analysis would take into account both the 'situated nature of accounts as well as the institutional practices and social structures within which they are constructed' (p.22). This view also fits with Clarke et al's (2015) situational analysis, which was used as an analytical framework during data analysis.

Andrews (2012) asserts that the terms constructivism and social constructionism tend to be used interchangeably and incorporated under the generic term 'constructivism', particularly by Charmaz (2014) in her evolved grounded theory method. Andrews (2012) summarises that constructivism suggests individuals mentally construct the world of experience through cognitive processes, whereas social constructionism is concerned with the social construction of reality. A critique of social constructionism is offered next and is followed by a description of constructivist grounded theory and why it has been chosen for this study.

3.3.6: A critique of social constructionism

In her 2003 book, *Social Constructionism*, Burr refers to the two broad forms of social constructionism as micro and macro, in preference to their previous labels of 'dark' and 'light' or 'strong' and 'weak', which both have positive versus negative connotations. Burr (2003) proposes that a prominent representation of these forms of social constructionism is in Foucauldian discourse analysis. However, confusion arises because both kinds of research can be referred to as 'discourse analysis'.

Cruikshank (2012) equates the relativist stance of social constructionism with scepticism and disputes this as an effective form of criticism. Similarly, Danzinger (1997) cautions that there is a kind of tension between social constructionism and the mainstream world it seeks to analyse. The concern is then whether social constructionist theory is able to generate its own theory or just 'a kind of guerrilla warfare upon mainstream psychology from the margins of the discipline' (Burr, 2003, p.21), therefore lacking credibility or the ability to generate theory.

The relativist stance also draws criticism from those that suggest there is an objective reality that exists beyond language (Andrews, 2012). However, as mentioned above and detailed below, Charmaz (2014) believes the introduction of relativism and subjectivity has benefited research and was a necessary development. She describes social constructionist researchers of the 1980s and 1990s who were not taking into account their own 'processes of construction of the research and the structural and situational encroachments upon it' (p.14). Rather than analysing the constructions of the world, they treated their analyses as

accurate renderings of the world. The following section provides a description of the evolving approach known as constructivist grounded theory and how it sought to move grounded theory on from the positivism of the early versions as well as the notions of a neutral observer and value-free expert.

3.3.7: Evolving approaches to grounded theory

Mills et al (2006) present the concept that there is a methodological spiral from Glaser and Strauss (1967) to the present. This spiral seems to largely bypass Glaser's work and focuses on developments in Strauss's work regarding symbolic interactionism and pragmatism. The spiral ends at constructivist grounded theory with points of departure along the way, depending on the researcher's ontological and epistemological beliefs. However, it retains the common characteristics of grounded theory of: theoretical sensitivity, theoretical sampling, constant comparative methods, coding, meaning verification, core category identification, memoing/diagramming, and the measure of rigour (McCann and Clark, 2003). Clarke et al (2015) summarises that by the new millennium there were several different emphases in grounded theory, which she characterises as: Glaser – positivist and objectivist; Strauss – constructivist, interactionist and interpretivist; Strauss and Corbin – procedural and post-positivist; Charmaz – the first fully interpretive constructivist. She also mentions her own work in situational analysis, which is an extension of grounded theory to the '(re)turn to the social' (Clarke et al, 2015). This development of grounded theory will be discussed in more detail below.

Thornberg (2012) refers to an 'informed grounded theory', which rejects naïve empiricism as well as theoretical forcing. Theoretical and research literature are neither dismissed nor applied mechanically. Literature is used as a possible source of inspiration, ideas, crucial reflections and multiple lenses, which is in line with abduction. Abduction was first introduced as a concept by Charles S. Pierce in 1958; and abductive reasoning is seen by later theorists as an essential component of grounded theory (Thornberg, 2012). Abduction refers to the process of studying facts and devising a theory to explain them (Richardson & Kramer, 2006). Abduction is proposed as a type of inference that is different to both induction and deduction, and is focused on finding explanations for observable facts. Abduction does not replace induction and deduction but refers to different stages of the inquiry (Richardson & Kramer, 2006).

Abduction is an essential concept within pragmatism, which shows a link back to Strauss and Straussian grounded theory on the methodological spiral as described by Mills et al (2006). MacDonald & Schreiber (2001), a student of Strauss, says, 'For Strauss, pragmatism was central to his thinking.' Pragmatism is a philosophical tradition that Strauss embraced whilst studying at the University of Chicago. The concept of pragmatism informed symbolic interactionism and assumes that society, reality and self are constructed though interaction (Charmaz, 2014). These interactions rely on language and communication and are dynamic and interpretive. More recently Charmaz (2017) has said that both pragmatism and constructive grounded theory foster grounded theory's 'openness to the world, and a belief in gaining knowledge though experience in it' (Charmaz, 2017, p.38). A discussion regarding constructivist grounded theory and the reason for it being the chosen methodology for this study follows.

3.3.8: Constructivist grounded theory

During the 1990s there was a move away from the perceived positivism in grounded theory toward an inductive, emergent and open-ended approach consistent with Glaser and Strauss's (1967) original statement (Charmaz, 2014). Kathy Charmaz is the first researcher to describe themselves explicitly as a constructivist grounded theorist (Mills et al, 2006). Charmaz (2014) states that her position is consistent with the form social construction takes today, and that there are strong currents of social constructionism in constructivist grounded theory. In keeping with the descriptions of social constructionism, symbolic interactionism and pragmatism above, the constructivist approach moves away from the unbiased researcher to the acknowledgement of the researcher's preconceptions and privileges. It requires the researcher to understand their own epistemology and ontology and to take into consideration how this affects the data collected and the analysis thereof. There is an acknowledgment that the researcher is the author of the construction of experience and meaning. Constructivist grounded theory highlights the flexibility of the grounded theory method, whilst resisting the mechanical application of it.

Unlike other versions of grounded theory, the constructivist version also locates the research process and product in historical social and situational conditions (Charmaz, 2017). This is also true of authors such as Clarke et al (2015), who describe a move from qualitative research holding sway over the micro (interpersonal) level to include the meso (social/organisational/institutional) and macro (broad historical patterns) levels, which were previously the domain of quantitative research. Clarke's contribution to constructivist

grounded theory is an interpretive qualitative method that also extends grounded theory to include the ability to conceptualise people within their wider context and how these are constructed.

In keeping with social constructionism, the narrative of the participants is embedded in the final research outcome, with the use of raw data in theoretical memos to keep the participant's voice and meaning present in the theoretical outcome (Mills et al, 2006). Furthermore, the value the researcher places on the participant's contribution meets the researcher's ethical obligation to 'describe the experiences of others in the most faithful way possible' (Munhall, 2001, p.540, quoted in Mills et al, 2006). In constructivist grounded theory, the researcher strives to maintain the participants' presence throughout, which is an important element of this study. Using the analogy of Mills et al's (2006) methodological spiral, where researchers identify their ontological and epistemological position and are able to choose a point on the spiral which feels theoretically comfortable, which in turn enables researchers to 'live out theory beliefs in the process of inquiry', I feel that my position, together with the need to capture and co-construct participants' meaning, demands that constructivist grounded theory is used. Furthermore, the study takes place within institutions such as health and social care settings, and constructivist grounded theory is able to take into account how such contexts shape participants' lives. A critique of constructivist grounded theory follows, with further justification for its use in this study.

3.3.9: A critique of constructivist grounded theory

In their critique of constructivist grounded theory, Breckenridge et al (2016) discuss the differences between traditional or Glaserian grounded theory and the evolved approach. They state that constructivist grounded theory has remodelled the original purpose of the traditional approach by attempting to interpret how participants construct their realities and in presenting multiple perspectives instead of conceptualising a latent pattern of behaviour. They add that the 'relativism inherent within constructivist grounded theory and the predetermined philosophical lens are fundamentally at odds with the general inductive nature of the classic approach.' (Breckenridge, 2012, para. 23). However, as Thornberg (2012) points out, Glaser makes no citations when he argues for his anti-philosophical stance, which is in turn interpreted as a positivist stance and brings us back round to the limitations of the concept of the unbiased *tabula rasa* researcher.

Glaser (2001) has criticised constructivist grounded theory for contradicting the openness of the original methodology by predetermining one particular lens through which to analyse data. Instead, classic grounded theory is presented as a general method, which can use any type of data and is not attached to any one theoretical perspective; it is essentially ontologically and epistemologically neutral. As such, Glaser (2005) has argued that discussions of ontology and epistemology are moot within classic grounded theory. This approach has been criticised as naïve, but Holton (2007) attempts to provide clarification of Glaser's position when they say, 'this is not to say that classic grounded theory is free of any theoretical lens but rather that it should not be confined to any one lens; that as a general methodology, classic grounded theory can adopt any epistemological perspective appropriate to the data and the ontological stance of the researcher (p.269).' This sounds similar to Mills et al's (2006) methodological spiral and is true of this study. I have carefully selected an epistemological perspective that is appropriate to the data and my ontological stance. Constructivist grounded theory, as described by Charmaz in *Constructing Grounded Theory* (2014), provides the researcher with the tools to carry out a grounded theory study, much as Strauss and Corbin (1998) did. It also encourages the development of analyses into theory construction, whilst maintaining the perspective rooted in symbolic interactionism, which 'sees people as active beings engaged in practical activities in their worlds and emphasises how they accomplish these activities. This perspective produces a dynamic understanding of actions and events' (Charmaz, 2014, p.263).

3.3.10: Summary

In summary, I concluded that that constructivist grounded theory provided an appropriate ontology for this study, which sought to understand the perceptions and experiences of stakeholders involved in the discharge from community hospital of older people living with frailty approaching the end of life. It provided a flexible methodology that enables all aspects of the discharge experience to be explored. Constructivist grounded theory acknowledged the role of the researcher in the analysis process and theory development and provided structure for data collection and analysis, which are discussed below.

3.4: Methods

To begin the methods section is a reminder of the questions that this study aims to answer:

1. How is discharge perceived and understood by stakeholders?

2. How is discharge experienced by stakeholders?

3. What structures and processes are in place to facilitate discharge?

As Charmaz (2014) said, 'Let your research problem shape the methods you choose' (p.23). In this section the research design is presented, together with a discussion regarding the approach taken to data collection, sampling and analysis, as well as issues of ethics and rigour.

3.4.1: Research setting

The study took place in four community hospitals in one community trust in England. The community hospitals comprised of one ward of 18–23 beds each. The wards provided in-patient rehabilitation in the form of 'step up' services from the community or 'step down' services from the acute trust. Health professionals on the ward included modern matrons, registered nurses, rehabilitation assistants, healthcare assistants, physiotherapists, occupational therapists, care managers, pharmacists, visiting medical officers and medical consultants who run the county's community hospitals. One of the hospitals was still being run by local GPs.

3.4.2: Recruitment to the study

3.4.2.1: Inclusion criteria

A target population was identified and inclusion criteria was created to identify appropriate participants in order to answer the study's question.

- The inclusion criteria for patients were:
  - NHS patients who were being discharged from a community hospital to a community setting. Their place of residence may be their home but it may also be a nursing home, the hospice or a family member's home.
  - Health professionals consider that it would not be a surprise if the patient were to die within the next six months.
  - Must have mental capacity to make informed decision/consent and undertake the required interview at the time when it was to take place.
  - Must speak sufficient English for a meaningful discussion, as there was no funding for an interpreter.

- The inclusion criteria for family/carers were:
  - Carers were defined as whomever the patient regards as their main source of practical and/or emotional support; they may live with the patient or visit regularly.
  - The patient must have consented to their discharge being discussed with family/carers.
- The inclusion criteria for hospital and community staff were:
  - Those who were directly involved in caring for the patient preceding and post-discharge. For example, in the hospital this could include a physician, nurse, occupational therapist, physiotherapist or healthcare assistant. In the community this could include a community nurse, hospice nurse, GP or community or hospice allied health professionals.
  - The patient must have consented to their discharge being discussed with hospital and community staff.

3.4.2.2: Patients and family/informal carers

Patients and informal carers were asked to participate in an interview regarding the patient's discharge from hospital back to the community. The interview was carried out post-discharge at a time and date chosen by the patient and family/carer.

Patients that met the inclusion criteria were identified by the Consultant Practitioner and the Advanced Clinical Practitioner at four community hospitals and by a ward sister at one community hospital. These professionals then approached patients to explain the study and gain permission for the researcher to contact the patient soon after discharge. The health professional then completed a permission form that included the patient's name, address and phone number, which demonstrated the patient's agreement to be contacted after discharge (see Appendix 4). On the patient's information sheet (see Appendix 5) there was a research telephone number so that the patient or carer could contact me if they needed to. The telephone number was for the research study only. If I was not on the ward the completed permission forms were kept in a file in a lockable room and the health professional would contact me to let me know it was there. I remained in contact with the ward to find out when the patient was discharged. If the patient was discharged to a nursing home, hospice or family member's house, a new contact number was collected.

I contacted the patient as soon after discharge as was practicable in order to accurately capture data during the interview. I checked again that the patient was still happy to participate in the research and reassured them that they could withdraw from the study at any time. During the visit I talked through the research aims and what was involved to ensure consent was informed. A copy of the information sheet was left with the patient. The patient consent form included consent for the researcher to talk to their family/carer and health professionals involved in their discharge from hospital. A third substantial amendment was submitted to the Health Research Authority (HRA) to include the option for the participant to be contacted again in the near future to talk further about life after the discharge from hospital. This was done because participants were readmitted to the community hospital, so I was keen to track this process and the experience of multiple admissions. One participant died during the second admission, so her experience was described by her carer. The other participant that was readmitted was back in hospital three weeks after admission and then readmitted to the acute trust 10 days later, therefore I was eager to find out more about the experience of what could be deemed a 'failed discharge', 'revolving door' patient or 'bed blocker'.

Interviews took place in the patient's place of residence, and family were either interviewed there or at their own home. Three participants were at a residential home and one was at a nursing home. All of them had been living at home prior to the hospital admission. The remaining six participants were at their own home. A letter was sent to the patient's GP to inform them of participation in the research. Three participants died before a letter was sent and in these cases I did not send a letter to the GP. Further sample description can be found in Table 1 below.

3.4.2.3: Health professionals

I liaised with hospital staff to identify who had been involved in the patient's care and discharge. These individuals were able to indicate which community services had been referred to. The patient and their family were also able to indicate which community services were providing input and therefore should be approached to participate in the interview. Health professionals were interviewed at their place of work in a quiet space if one could be found. One physiotherapist preferred to read from the computer, which limited where the interviews could take place. Service lead permission was gained to approach hospital and community staff directly.

3.4.3: Issues relating to the recruitment of participants

Originally, purposive or initial sampling was to be based on the participants who had experience of the phenomena of discharge from acute hospital to the community *in the last weeks or months of life* (Morse, 2010; Charmaz, 2014). Primarily, participants were to be identified by the palliative nurses at three acute hospital sites. However, this method did not yield any recruitment despite constant contact and encouragement. I was also able to include the end of life facilitators who had been put in post since the study had begun, but they were also unable to help identify participants. After discussing the study with a community geriatrician, and gaining their support, a substantial amendment was submitted to the Health Research Authority to move recruitment to the community hospitals. Consequently, the study was based at four community hospitals.

A second substantial amendment was submitted to recruit via a GP surgery, with letters being sent to patients who had recently been discharged from hospital and where the GP would not be surprised if the patient were to die in the next six months. There were two mail outs, with a total of 18 patients contacted. This method yielded no recruitment, which was not surprising as people who have recently been discharged from hospital, who are also older with frailty, may not feel up to responding to a letter. The lack of recruitment at the acute trusts appeared to be due to a reluctance in the health professionals to engage in the research as they were protective of their patients and thought it may cause them some sort of distress. I visited weekly and tried to support recruitment, but the nurses felt that none of their patients were appropriate for the study. The advanced practitioner nurse at the community hospitals, who was my main point of contact, was sympathetic to my study as she too was doing a PhD and she had also found recruitment difficult. Furthermore, the community geriatrician that lead the team was very supportive. Her leadership appeared to be beneficial to encouraging other health professionals to engage in recruitment.

3.4.4: Sampling

The professionals who were key to helping with recruitment were a consultant practitioner and an advanced clinical practitioner, who were well placed to make recommendations due to their role and scope. The consultant practitioner roles were introduced to improve patient outcomes, strengthen leadership and provide a clinical career pathway for senior and experienced nurses and allied health professionals (AHPs). They are registered healthcare professionals who work beyond the level and scope of their registered status. They typically become competent in areas that have traditionally been the remit of a medical practitioner.

Initial sampling in constructivist grounded theory builds on the work of Glaser and Strauss (1967), Glaser (1978, 1998, 2001), and Strauss and Corbin (1990, 1998), and is described by Charmaz (2014) as being based on the inclusion and exclusion criteria. To aid the analysis, a situational analysis messy map was used, which also highlighted when saturation was achieved (discussed below). In line with grounded theory, coding and analysis were iteratively carried out during data collection. Data was analysed after three 'cases', which consisted of 15 participants, and themes were emerging at that point. After a further seven 'cases' were analysed, very few new themes were emerging, therefore it was considered that data saturation was reached. Theoretical sampling was then used to 'seek and collect pertinent data to elaborate and refine categories' in the emerging theory (Charmaz, 2014) – see Tables 1 and 2.

Patient	Age range	Informal carer(s)	Community hospital health professionals	Community health professionals	Number of participants
Hazel	100+	Brother-in-law Family friend	Nurse Occupational therapist	Care home manager	6
Amy	80–90	Daughter Grand-niece	Occupational therapist Physiotherapist Nurse	Hospice nurse	6
Alastair	70–80	Daughter	Consultant Nurse	Nursing home manager	4
Zoe	90–100	Friend and sister	Occupational therapist Nurse	Occupational therapist	6
Mae	80–90	Nil	Physiotherapist Nurse	Physiotherapist Care home manager	5

Ivy*	80–90	Daughter*	Occupational therapist	Rapid response nurse Physiotherapist	5
Jane	90–100	Neighbour	Occupational therapist Physiotherapist Nurse	Frailty nurse	6
Claire	90–100	Niece	Occupational therapist Physiotherapist Nurse	Care home owner/manager Physiotherapist	7
Andrew	80–90	Daughter and wife	Therapy assistant	Physiotherapist	5
Iris	80–90	Son	Occupational therapist Physiotherapist	Not referred for community support at the time of interviewing	4
* Interviewed twice: after first and second discharge from hospital.					**Total 55**

Table 1: Initial sample September 2018 – February 2019

Title	Location	
Consultant Community Geriatrician	Community and Community Hospital	
General practitioner	Community	
Therapies lead	Community hospital	**Total 3**

Table 2: Theoretical sample summary

Constructivist grounded theory, led by Charmaz (2014), defines theoretical sampling as 'seeking and collecting pertinent data to elaborate and refine categories in your emerging

theory' (p.192). Theoretical sampling in constructivist grounded theory is similar to Glaserian and Straussian grounded theory, in that it is viewed as a process of collecting data to further explore concepts that have developed during prior analysis of the initial/purposive sample (Charmaz, 2014; Corbin and Strauss, 2014; Glaser and Strauss, 1967; Glaser and Strauss, 1999). Themes regarding patient choice, control and decision making were arising, as were the mismatches in expectations between therapies and nursing/medical staff. Therefore the community hospital's therapies lead was interviewed. They were also able to talk about the gap in therapy input after discharge whilst waiting for limited community resources to commence community rehabilitation. The therapies lead was able to talk about the reaction of family members to the reduced amount of rehabilitation provided at community hospitals. A general practitioner was interviewed about recuperative care beds, community hospital wards closing and the limitations in community resources after discharge. Themes regarding lack of flexibility of community services due to resource limitations arose and were discussed. The general practitioner was also able to give some insight into the family dynamic after discharge. Finally, the consultant geriatrician providing medical input to the community hospitals and in charge of the HUB meetings in the community was interviewed regarding the aims of both the new frailty team and the community hospital, as it was emerging there was a difference between the medical focus and rehabilitation focus of health professionals, which was causing discord. She was also able to give perspective across the discharge process as the HUB is a multidisciplinary over-75 service that is orientated toward hospital admission avoidance. The team is made up of the consultant geriatrician, advance clinical practitioners, community pharmacists, general practitioner, a care manager from social services, a health and social care coordinator and a mental health nurse as well as representatives from community teams such as Intermediate Care. The community geriatrician was also able to give insight into the staff perspective of communication with patients.

3.5: Data collection

3.5.1: Interviews

In order to capture and analyse what was being said, data collection was derived from fieldwork interviews as they aimed to help to 'understand the world from the subjects' point of view, to unfold the meaning of their experiences and to uncover their lived world prior to scientific explanations' (Brinkmann and Kvale, 2015, p.3). The interviews were semi-

structured, which was suited to enabling participants to fully express themselves in their own time and in a familiar environment, and to 'unfold the meaning of their experiences, to uncover their lived world', which is appropriate for the participants of this study (Brinkmann and Kvale, 2015). An interview guide was used which was based on the NIHR funded study 'Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study' (Hanratty et al, 2014). This was referenced for credibility and best practice purposes, as it was a robust study that examined transitions between care settings at the end of life. The study is discussed in detail in the Literature Review (Section 2.7). The semi-structured interview guide was designed to allow and enable participants to talk about their experience of the discharge, but to keep the conversation focused on the main topics (see Appendix 7: Interview Guide). The interview guide encompassed what Charmaz described when she highlighted the good fit between grounded theory and interviewing: 'open-ended yet directed, shaped yet emergent, paced yet unrestricted' (Charmaz, 2014, p.85). The interviewing method in grounded theory enables the researcher to learn about the world and construct theory, capture and analyse discourses with accuracy and plausibility. To guide me further, I used the guidance for conducting interviews provided in *InterViews* (Brinkmann and Kvale, 2015), which is summarised in Table 3.

Guidance	Suggested action	Action taken in this study
Setting the interview stage	Encourage interviewees to describe their points of view. Interviewer show attentive listening, show interest, understanding and respect. Briefing and debriefing before and after the interview. Allow time for comments after debrief.	Briefing and debriefing used before and after interviews. Allowed participants to talk about what was important to them. Showed empathy and respect for participant experiences.
Scripting the interview	Interview guide which structures the course of the interview. It will depend on the study whether the guide is followed strictly or not. Seek meaning clarification.	Outline of topics to be covered included in the interview guide. See Appendix 7. Interviews allowed participants to deviate from the script in order to explore what was important to them. The interview guide was used to ensure no topics were missed. The interview guide of an NIHR funded study was used to ensure credibility.
Interviewer questions	Questions should be brief and simple. An introductory question may concern a concrete situation. Use open questions.	Participants were always asked for their thoughts on the discharge process as that was the key theme of the study.
Second questions	The interviewer needs to learn to listen to what is said and how it is said, be sensitive to situation cues instead of focusing all attention of the interview guide.	Issues that the participant identified were explored further.

Table 3: Brinkmann and Kvale guidance for conducting interviews (2015)

Criticisms have been levelled at data collection strategies of grounded theorists such as Glaser and Strauss (1967), including the potential for the interviewer to dominate the conversation, and power issues related to the differing agendas of the participant and

interviewer (Charmaz, 2014). However, the egalitarian aim of constructivist grounded theory interviews hopefully negates these issues. This is because there is an attention 'to the situation and construction of the interview, the construction of the participant's story and silences, and the interview-participant relationship as well as the explicit content of the interview' (Charmaz, 2014, p.91). The interview is viewed as an emergent interaction, not a mere mirror of reality. To this end, constructivist grounded theory differs from traditional grounded theory. Glaser (1978, 1998, 2001) continues to argue for notetaking, but Charmaz (2014) feels omitting recording and transcription means that the situational elements, as well as the construction of the interview, are missed. Recording and transcribing enables the preservation of tone, tempo and silences, as well as statements (Charmaz, 2014). In line with constructivist grounded theory, I paid attention to language and discourse, whilst encouraging 'participants to reflect upon their experiences … in fruitful ways for advancing theory construction' (Charmaz, 2014, p.95).

Charmaz (2014) described the difference between constructivist and objectivist grounded theory interviews as emphasising and eliciting the participant's defining of terms, situations and events, and trying to tap in to his or her assumptions, implicit meanings and tacit rules; whereas objectivist interviews may tend toward obtaining information about chronology, events and problems that the participant seeks to resolve. Therefore, constructivist grounded theory fits well with descriptive interviewing as described by Brinkmann and Kvale as, seeking 'to chart key aspects of the subject's lived world. They may further attempt to develop theoretical conceptions of a topic … to inductively develop an empirically grounded theory' (2015, p.133). For this study I was keen to look at what was perhaps considered problematic by the participant but also to give them the tools, ability or opportunity to suggest solutions or how they would have preferred the discharge to go. In doing so, there is also the opportunity for the participant to talk about what is meaningful to them during the process. The results are then rooted in the participant responses, which fits well with constructivist grounded theory whilst meeting the aims of the study. To enable some participants to articulate their views I trialled the use of a solution-focused technique called the 'scaling' question. The scaling question is used to help interviewees gauge their subjective experience. It helps to explicate how close the participants' experience was to their desired experience. 'Scales offer an intuitive logic that is readily accessible. Most people find it reasonably easy to establish a scale. They know for themselves the meaning of some of the points, and they are often able to tell you what a point represents for them' (Jackson & McKergow, 2007, p.94). It is then possible to ask the interviewee what would

have needed to happen in order to move up the scale, to get closer to the perfect discharge. The scaling question was particularly good at helping the respondents to describe how good or bad they felt the discharge was and helped to keep interviews with busy health professionals as brief as possible, whilst enabling the capture of rich data. Whilst the scale was subjective, it was also interesting to see how a hospital health professional might compare the discharge with a community health professional, showing a clear contrast in perspectives of the same phenomenon. The scale was not used with patients and their informal carers, as it was seen as more of a trigger for professionals to reflect. Health professionals are better placed to judge a discharge against others they have been involved with in their career in a way that patients and informal carers cannot, as they do not have the experience to refer to and cross-check with. Using the scale was a sort of strategic reductionism that made sense to participants and enabled them to generate possible solutions to discharge issues. For example, if the discharge was considered an 8, I asked what would make it an 8.5 or 9. This helped participants to think about why the discharge was an 8 and not a 10, and what they would have like to have done differently or what else could have happened to make the discharge better. The most interesting response prompted by this question was when a participant identified that there was a difference between a system-focused score and a personal/professional score. This will be discussed in more detail in Section 5.2.2. The scaling did not dominate the interviews or findings and was merely a tool. I sought to interview in such a way that conversations were collaborative encounters where the researcher and participant were equal contributors with different contributions (Millar, 1997). At a time when control is being taken away by disease and medical or social care processes, promoting a sense of enablement or self-efficacy whilst participating in this study was very important. Whilst participants would not necessarily be able to improve their own situation, there is potential for them to improve the experience of people in a similar situation in the future and for the solutions generated to permeate meso, micro and macro levels, which is a good fit with constructivist grounded theory and Clarke et al's (2015) mapping, discussed further in Section 3.7, with regard to data analysis.

3.5.2: Field notes

Immediately after each interview field notes were recorded. These recorded the setting of the interview, non-verbal communication, mannerisms and body language of the participants that cannot be captured on the digital recorder. I also wrote down anything significant the participant might have said once recording stopped, as well as salient points

from the interview. The recording and subsequent review of the field notes was helpful in the data analysis phase, but also facilitated my own reflection on the interview. Notes would be made of how to improve future interviews or specific points that could be explored further with family members or health professionals. An example field note extract is provided in Appendix 8.

3.6: Data analysis

The following section describes the data analysis process. Interviews were audio-recorded on a digital recorder and transcribed verbatim by a transcriber. I listened to the recordings and made notes to include subtleties that may have been missed in transcribing. The original text was revisited in order to ensure subtleties were not overlooked and to record 'in vivo' codes that were suggested by the respondent themselves (Urquhart, 2013). An analytical product rather than a purely descriptive account was the goal of the study. The principles of grounded theory coding guided the coding process.

3.6.1: Grounded theory coding and analysis

Allen (2003) wrote a personal reflection of using grounded theory in order to guide those in industries or sciences which have not used the method before. They describe the coding process in detail and discuss the benefits and issues. In conclusion, they found that grounded theory coding was reliable and rigorous, as it was grounded in the data, but that the iterative process required patience and analytical skill. They commented on how Glaser and Strauss (1967) and later Glaser (1978, 1992) 'do not instruct the reader in a prescribed mechanism for performing the coding', but describe the 'conceptualisation of coding' rather than provide a clearly defined coding process (Allen, 2003, p.1). Charmaz (2014) provides a little more detail on how to code, and data coding followed these guidelines, which say that grounded theory coding uses two main phases: an 'initial phase' that names each word, line or section of the data and a 'focused phase' that sorts, organises and synthesises large amounts of data using the most significant or frequent initial codes (Charmaz, 2014). During this phase decisions are made about codes, which are then tested against the data. If they do not work, the researcher goes back to line-by-line coding. In constructivist grounded theory, all incidents are compared, including the routine activities, not just dramatic incidents. This constant comparative method was employed during the initial phase as I reviewed the material and developed codes line by line and section by section – example in

Appendix 9. *In vivo* codes that used participant's actual words were used to ensure accuracy and relevance.

Data were hand-coded, and coding maps were created as a version of a grounded theory memo. Memos are an essential method in grounded theory because it prompts the analysis of data and codes early in the process (Charmaz, 2014). The individual maps allowed me as a visual learner to analyse the codes in any way that occurred to me during the coding of each transcript. These maps as memos enabled me to capture my thoughts, as well as the comparisons and connections being made. Written memos were also completed, which often summarised thoughts and connections that had occurred during the mapping process. There was no attempt to exclude any elements in the data, rather to allow all elements their rightful place in the total picture as it emerged. Due to the evolving nature of the grounded theory approach, interviewing continued until no new properties emerged in the developing categories. This enabled data saturation of the categories, which were then sorted into an integrated theoretical statement (Charmaz, 2014). The use of situational analysis maps as an analytical framework is discussed in more detail in the next Section, 3.6.2.

3.6.2: Analytical framework

A number of frameworks were considered for this study, including Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1977), which bears a resemblance to Strauss and Corbin's Conditional Matrix (Strauss & Corbin, 1998). Both seek to map individuals surrounded by their family, organisation, community, region, nation and so on. However, constructivist grounded theorist Adele Clarke (Clarke et al, 2015) highlighted that this is related to modernist reasoning that the world is assumed to be separable. To remain in keeping with the constructivist grounded theory methodology Clarke's situational maps were used.

Strauss and Corbin urged investigators to be more sensitive to conditions, actions/interactions and consequences of a phenomenon, and to order these conditions and consequences into theories. To facilitate this, they offered a useful tool called the 'conditional matrix'. They felt that in the selective coding phase, in order to complete the grounded theory, it is necessary to create a conditional and consequential matrix, an 'analytic device to stimulate analyst's thinking about the relationships between macro and micro conditions/consequences both to each other and to the process' (Strauss and Corbin, 1998, p.181). The matrix helps to frame a 'story', which is a key aspect in formulating the grounded theory. However, whilst there is some benefit to distinguishing between micro

and macro or individual and society, Clarke's fundamental question is 'How do these conditions appear – make themselves felt as consequential – inside the empirical situation under examination?' (Clarke et al, 2015, p.72). Clarke developed the situational map out of the work Strauss and Corbin did on the conditional matrix, with the aim of provoking new ideas and to help the research to interpret the field differently and more deeply.

Situational maps aim to define the ontologically different types of elements (human and non-human) that are in a situation (Mathar, 2008). The elements are jotted down quickly as they occur, producing a messy map much like brainstorming. 'Who and what are in the situation? Who and what matters in this situation? What elements 'make a difference'? (Clarke, 2005, p.87) The symbolic meaning of the elements must not be forgotten. Maps do not remain messy, as they are done at each phase of the study and help to achieve theoretical sensitivity. The use of such a dynamic understating of actions and events was of benefit in this study because of the complex interaction between patient, family and health professionals, as well as between these individuals and the processes, systems and policies involved in the discharge and care of the patient. Mapping provided a way of conceptualising these elements and how they related to each and how they interacted. Clarke et al provide a strategy for mapping which is helpful to the novice researcher but encourages 'tinkering on your own' thus not forcing researchers to do anything that is uncomfortable (Clarke et al, 2015, p.178). Another benefit of the maps is that they provide a visual aid to information sharing, which can be valuable when team working, presenting findings or discussing with supervisors.

As recommended by Clarke et al (2015), mapping was used during the memo-writing process, which Charmaz (2014) describes as the 'pivotal intermediate step between data collection and writing drafts of papers' (p.72). Grounded theory uses memo-writing as a method because it crucially prompts the researcher to analyse the data and codes early in the research process, keeping them involved in the analysis and increasing abstraction. The standout codes take the form of theoretical categories through the process of successive memos, thus aiding theoretical saturation.

As the data were subjected to deeper analysis and comparative scrutiny in the focused phase, a larger map was employed to map out the themes emerging from the smaller, individual maps. For an example of a coded transcript and map as memo see Appendices 9 and 10. The maps allowed me to sift through large amounts of data and to categorise it. The larger map also allowed for a deeper understanding of the complexity of the discharge

processes and procedures as experienced by the stakeholders. The map allowed for grouping of codes into larger themes and for the interconnections between codes and themes to be rendered visible. Greater theoretical sensitivity was enhanced by the use of a map as it enabled me to understand and define phenomena in abstract terms, as well as demonstrating abstract relationships between phenomena (Charmaz, 2014). Meaning was then discerned from the emergent patterns, with the defining of the distinctive properties of my constructed categories. The strongest hypothesis was tested against the data; and the higher-level concept of 'drive to discharge conveyor belt' was identified as the core category. The subcategories of 'resource limitations', 'mismatch in expectations', 'concepts of choice and control' and 'carer burden' were also identified. The subcategories were heavily influenced by the core category, but the data described a complexity of situation where the subcategory of carer burden was also influenced by the other three subcategories. A conceptual framework diagram was created to illustrate this complexity and the relationship between the categories (see Figure 12 in Section 4.2). 'Carer burden' was a significant category but was not the higher-level concept that drew all the data together. The core category, categories and subcategories are described in detail in the Findings chapter, see Section 4.2.

3.6.2.1: Intersectionality

Intersectionality is then used to interrogate the dominant discourses or truths and their power in relation to the lived experience of participants. The research questions of this study were prompted as described in Chapter 1: Introduction. Intersectionality is a conceptual framework, which has roots in social justice research and struggle. The term was coined in 1989 by Kimberlé Crenshaw. Intersectionality is an appropriate theoretical paradigm for this study as it enables the critique of the complexity of people, their lives and choices, in contrast with the uniformity of the discharge process and the expectations of how people will behave once they are home and what services they will receive.

Intersectionality enables the researcher to do this by examining the interaction among categories of difference in 'individual lives, social practices, institutional arrangements and cultural ideologies, and the outcomes of these interactions in terms of power' and is compatible with the situational maps used in data collection and analysis (Corus & Saatcioglu, 2015). Essentialist notions that define social groups, such as older people or 'the frail', as homogenous are challenged by intersectionality. The complexity and difference within the same social group can be considered through multiple identity axes and structural

dynamics. Corus and Saatcioglu (2015) argued that a more nuanced scholarship may introduce considerable complexity and ambiguity into analysis and prevent stereotyping that has a negative effect on patient/health professional encounters.

Collins and Blige (2016) describe intersectionality as:

> *a way of understanding and analysing complexity in the world, in people and in human experiences … Intersectionality as an analytic tool gives people better access to the complexity of the world and of themselves … People use intersectionality as an analytic tool to solve problems that they or others around them face.* (p.2)

It is seldom one factor that shapes the events and conditions of social and political life. Rather, there are many diverse and mutually influencing factors. Intersectionality enables us to understand how people's lives, the social inequality they experience and organisational power are shaped not by a single axis of social division, such as race, gender or class, but by many axes that influence each other and work together. Intersectionality has a framework that can shed light on experiences, whilst taking into account the interconnected nature of multiple disadvantages and the complexity that causes marginalisation in healthcare (Corus & Saatcioglu, 2015).

Hankivisky and Chrisoffersen (2008) looked at intersectionality as a way to better understand and respond to the '"foundational" causes of illness and disease, which the health determinants perspective seeks to identify and address' (p.271). They concluded that the intersectional paradigm provides a way of rethinking the understanding of determinants of health. They acknowledge that the intersectionality framework complicates everything because the approach requires moving beyond singular categories of identity to a more nuanced understanding that embraces the complexity of how health and illness are influenced by multiple determinants. Embracing complexity enables a greater understanding of social inequities which manifest in health inequities and therefore has the potential to create more accurate and inclusive knowledge. In turn, this knowledge can inform the development of responsive and inclusive services and policy (Hankivisky & Chrisoffersen, 2008).

3.6.3: Data management

Data was stored in accordance with General Data Protection Regulation (GDPR), as well as the Data Protection Policies of the University of Kent (UoK), as sponsors of the research, and the relevant Hospital/Community Trusts, with specific reference to patient identifiable data

and the relevant confidentiality clauses. This ensured that I worked to appropriate confidentiality standards. All audio recordings and other relevant files (e.g. addresses where these needed to be recorded for conducting of interviews in patient's homes) were kept in a password-protected file; the password was kept separate to all other study materials. Interviews were recorded on a digital recorder and transferred straight after the interview onto a University computer. The recordings were then immediately deleted from the digital recorder, leaving only the files on the university server. These files were only heard by the researcher and a transcriber. A transcriber signed a confidentiality agreement and had no access to the data following completion of transcription. Any files that needed to be emailed to the transcriber were transferred via their encrypted upload service.

Transcribed data was identifiable by the participant's unique study ID only, and any reference to the participant's name was not included in the transcripts. The code sheet linking the participant's name to their study ID was kept separate from all other study materials. Respondents' personal details (name, address, telephone number) were not recorded on any study data collection instruments or transcripts from audio recordings of interviews.

Each respondent was allocated a code as they entered the study, by which they were known throughout. A letter indicated if they were a patient (P), family member or informal carer (F), healthcare professional in the hospital (H) or healthcare professional in the community (C). A number was allocated sequentially, for example P1 was the first patient to be interviewed and F2 the second family member or another informal carer, for example, P1.F2. This identifier replaced participant names on all stored study documents. All data was analysed in an anonymous format. The code sheet linking the participants' names and contact details to their identifying number was kept separate from all other study material in i) a locked fire-proof filing cabinet and ii) a password protected electronic file at UoK. All computers used to collect or store data were password protected. All original data was stored in compliance with the Data Protection Act. For the reporting of the findings, patient pseudonyms replaced the ID code in order to make the findings easier to read. The pseudonyms were not related to the patient's actual name. All family members and health professions were referred to, for example, as 'Amy's daughter' or 'Jane's community occupational therapist'.

3.7: Ethical considerations and challenges

3.7.1: Ethics committee review and permissions

The study was submitted to the National Research Ethic Service (NRES) and the Research Ethics Committee (REC) meeting was held in May 2017. Approval was given in June 2017 – see Appendix 11. The following figure outlines the permissions gained and amendments made to ensure NRES standards were met.

• Good Clinical Practice (GCP) training, May 2017 • Insurance documents arranged via UoK, May 2017 • Research passport occupational health, completed May 2017 • Disclosure and Barring Service (DBS), July 2017 • Acute trust confirmation of capacity and capability, July 2017 • Acute trust research passport, July 2017 • Acute trust Letter of access, August 2017 • Community trust permission to conduct the study, August 2017 • Community trust Letter of Access, August 2017 • Community trust confirmation of capacity and capability, August 2017
• Substantial amendment, April 2018, community nurses and community hospices teams to help with recruitment. Supporting documents provided were: amended protocol, information sheets and consent forms. [This strategy was never implemented.] • Second substantial amendment, May 2018, to recruit via GP surgery. Supporting documents provided were: amended protocol, Information Sheets tailored for new data collection stream, Consent forms tailored for new data collection stream, Permission form with the addition of contact details, Letter from GP surgery. • Third substantial amendment, August 2018, to recruit via the community hospitals. Supporting documents provided were: amended protocol, amended consent forms.

Figure 10: Study permissions and amendments

In this study the ethical principles of respect for autonomy, justice, non-maleficence and beneficence guided the study design. This included the process of consent, maintenance of anonymity and confidentially, and protecting participants from harm or distress during the interview process.

3.7.2: Upholding ethical principles

The transition from hospital to the community, and potentially to a different setting in the community, is an extremely difficult time for the patient, family and friends, particularly when the patient is becoming frailer, with more health and social care needs. Every effort was made to respect the participant's dignity at this time. As the interviews aimed to discuss the discharge process and not the patient's diagnosis and prognosis, it was hoped this would reduce the amount of intrusion. I endeavoured to interview the patient and their family either on the same day or soon after to avoid a situation where the researcher contacted the family member after the patient had died. No patients died after giving consent but before family members and health professionals were interviewed. If the patient was identified as a possible participant but died before being interviewed the 'case' was not included in the study as the patient had not consented to family and health professionals being interviewed, plus the patient voice was key to the study. In one instance I arrived to carry out the interview but it was clear the participant had deteriorated since the interview was arranged and was very close to the end of life. The interview did not go ahead and the participant died three days later. Recruitment was approached with the four-principles approach at the fore, which includes non-maleficence i.e. to do no harm to any participants (Beauchamp & Childress, 2009). To further ensure non-maleficence, I extensively discussed the study with the Consultant Geriatrician and their Frailty Team, who agreed to support the research and to identify participants based on the inclusion and exclusion criteria but also with their clinical reasoning and knowledge of the patients, thus reducing the risk of potential coercion. My second supervisor (Consultant and Clinical Lead, Palliative care) advised on the most appropriate recruitment approach.

Once in a setting with health professionals who were engaged in the recruitment process, I found that older people living with frailty were happy to engage in research and to talk to me about their experience of being discharged from hospital. As the study progressed, I discovered that the research was as much about the informal carer as the patient. Many informal carers were pleased to have someone listen to their story of stresses and anxiety around the discharge and community care of their older relative/neighbour/family friend. It

enabled them to discuss things often ignored by health professionals. To this end, the principle of autonomy was upheld. It was also maintained in the consent process, where information sheets and verbal explanation of the study helped to ensure that informed consent was gained. Participants were reminded that they did not have to take part and could withdraw at any point. Information sheets and the interview schedule wording were discussed with a Patient and Public Involvement group, which is discussed further below in Section 3.8.1.

From the aspect of beneficence, patients, informal carers and health professionals were keen to take part in the study in order to improve the discharge process for stakeholders in the future. From the perspective of non-maleficence, there was the potential for participants to become distressed when discussing their experiences. I am experienced in working with patients at the end of life as an occupational therapist and confident using strategies to manage distress, including a reminder that they can stop the interview at any point and signposting to sources of help. Signposting is also important as I am aware that I am not in the role of practising occupational therapist at present. As an occupational therapist, I had regular mental capacity training, and interviewing would cease if the patient appeared to have lost capacity since being discharged. (See Sources of Support leaflet in Appendix 12.) I have experience in providing Advance Care Planning training to hospital staff and am therefore aware of the issues that hospital staff struggle with. Having worked as an occupational therapist providing rehabilitation for the elderly, as well as in palliative care in the community, I am aware of the challenges that community staff face and was mindful of these when carrying out data collection. I was prepared to signpost to occupational health, the palliative care team or an end of life care facilitator (hospital or community) and line manager, but this was not necessary.

All interviews were conducted by the me at a convenient location for the interviewee, as discussed above. Where data was collected in a patient's home or other community setting, interviews were scheduled to occur during the working day and the researcher had two mobile phones in case of emergency. In the event that a participant became distressed, the following guidelines were prepared:

- Offer support and empathetic listening (see Appendix 12 – Sources of Support sheet).
- If still distressed, offer to contact a source of help.

- If a patient requests, feedback (the content of which will be agreed with the participant) will be provided to the healthcare professional who is primarily responsible for their care, if applicable.

- In case of illness, contact the healthcare professional most readily available to offer help, including their GP.

During data collection, there were only two occasions where participants became upset. Both times it was the daughter of a patient. The first daughter of a participant got tearful recounting a very difficult nine months where her father had been admitted and discharged from hospital four times. She was very concerned about her father's wellbeing and had recently come to the realisation that he had very little time left to live. She was also relieved that her father was now clean, out of pain and well cared for. I offered to stop the interview, but she was keen to continue talking about the difficult time and asked to speak to me alone after the interview with her father. During that conversation she showed me photos of his flat to justify her strong feeling of injustice. During her battle with ward staff she had engaged the local Member of Parliament (MP) in the dispute. I checked if there was anyone else I could signpost her to, but as the MP was involved no further support was required. However, she seemed relieved to be heard, as was the daughter of another patient who was not doing well post-discharge, falling regularly and getting stuck in her chair. The second daughter looked tearful but never became distressed, so we continued. She identified that what she needed in order to feel less upset was practical support as she was struggling to manage the care of two elderly relatives with increasing health and social care needs. I provided the Sources of Support leaflet and called the Intermediate Care Team to let them know that since their assessment, a week earlier, their patient could no longer mobilise. This was in accordance with the consent form, that if the participant is at risk of harm I would raise it with the relevant services, with the participant's permission. In this instance I had the daughter's and patient's permission. As a result of my call, a nurse was sent to the patient and she was readmitted to community hospital as she was not safe on her own at night due to her reduced mobility. In the protocol it was said that if I had any concerns relating to safeguarding or bad practice then the Safeguarding Team at Kent County Council would be notified after discussing with the respondent. If concerns are in relation to the patient's stay in hospital, the hospital Safeguarding Officer would be notified. I did not have to do this as the one instance of reported bad practice was already under investigation. However, there was a case where the discharging team had said a community support

service was going to pick the patient up in the community. As I was keen to interview this service about their role, I called around to find the appropriate person to interview about their input with the patient straight after discharge. This is when I found out that the service had not heard of the patient and that somehow the patient was not being cared for by them post-discharge. In this instance I reported back to the person on the ward who had made the referral and they were able to take it up with the Care Manager at the local HUB meeting to ensure the service started to provide the much-needed support (see Section 3.4 for HUB definition). Finally, there was one other situation where, with permission of the informal carer who was a neighbour, I raised concerns with the patient's GP practice that the neighbour was using dangerous lifting techniques that were putting both the patient and neighbour at risk of harm. The patient was also relying heavily on the neighbour to provide support about four times a day in between four double-handed care calls a day. The neighbour was reporting that she was physically and emotionally drained. Furthermore, she was moving away and would not be available to provide this level of support on an on-going basis. The deputy manager of the surgery took the case to the HUB and a frailty nurse was assigned to review the patient's situation. Again, the carer seemed relieved to be heard and action taken on her behalf.

Justice was considered in that only patients deemed by the recruiting health professional to have capacity were identified as being appropriate for the study. The health professionals identifying possible participants were well trained in mental capacity and only recommended individuals whom they considered had capacity to consent to participate. The concept of capacity comes from the *Mental Capacity Act* 2005, which was implemented in 2007. The Act sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time. It is a 'decision-specific' test. A particular medical condition or diagnosis cannot result in someone being labelled 'incapable'. Section 2 of the Act makes it clear that a lack of capacity cannot be established merely by reference to a person's age, appearance, or any condition or aspect of a person's behaviour which might lead others to make unjustified assumptions about capacity.

Before deciding that a person lacks capacity, health professionals consider the two-stage functional assessment of capacity outlines in Figure 11 below.

Stage 1. Is there an impairment of or disturbance in the functioning of a person's mind or brain? If so,
Stage 2. Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision? The MCA says that a person is unable to make their own decision if they cannot do one or more of the following four things: • understand information given to them • retain that information long enough to be able to make the decision • weigh up the information available to make the decision • communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.
Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals. The assessment must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? You should be able to show in your records why you have come to your conclusion that capacity is lacking for the particular decision.

Figure 11: Mental capacity functional assessment from 'SCIE Mental Capacity Act 2005 at a glance' (2016, para. 12)

Justice and autonomy are discussed further in the Chapter 5 in relation to intersectional examination of the findings. The four principle approach is also discussed further in relation to carer rights.

3.7.2.1: Reflexivity

It is worth noting the influence of symbolic interactionism on constructivist grounded theory. Symbolic interactionism has philosophical roots in the University of Chicago during the early twentieth century, where Glaser and Strauss were active from the 1950s. It's benefit to grounded theory researchers is that it enables the combining theory and method, without forcing data and ideas into prescribed concepts. Charmaz (2014) described symbolic interactionism as 'a dynamic theoretical perspective that views human actions as

constructing self, situation, and society. It assumes that language and symbols play a crucial role in forming and sharing our meanings and actions' (p.262). The symbolic interactionism perspective recognises that our actions are in response to how our situation is viewed. It offers a 'world-view and language for conducting grounded theory studies' (Charmaz, 2014, p.284). Symbolic interactionism also encourages a reflexivity whereby the researcher needs to be aware of their emotions and how they enter both the research relationship and the findings. Charmaz (2014) stated that the symbolic interactionism perspective fosters the development of the kind of reflexivity that constructivist grounded theorists aspire to.

As I am a trained occupational therapist, I needed to be aware of how my clinical background and experience of therapeutic interviewing may have influenced the research interviews. Hutchinson and Wilson (1994) critiqued research and therapeutic interviews and stated that, 'despite conventional claims regarding fundamental differences between research and therapeutic interviews, at least as many commonalities are identifiable. Interviewing in research and in therapy is challenging, requires the interviewer to be aware of the interview purpose, the theoretical model that undergirds the interview process, and the relevant methodological issues' (p.313).

They found that the objectives of therapeutic and research interviews overlapped and that forms of interviewing involve 'a process of unveiling personal feelings, beliefs, wishes, problems, experiences and behaviours' (Hutchinson & Wilson, 1994, p.313). Dissimilarities in the two forms of interviewing identified were the theoretical models underpinning the interview. The direction in therapeutic interviewing is derived from the framework as well as from the client and the data, with an aim of intervention rather than analysis. Other dissimilarities identified were the interview focus and participant motivation. However, there were many similarities identified which crucially overlap with legal-ethical standards, management of privacy, anonymity and confidentiality, the ability to build rapport and to be reflexive and sensitive to the participant.

The occasions that stood out as being influenced by my training were the identification of harms that a non-clinical researcher may not have thought of as significant: for example, an informal carer drag-lifting, which is a manoeuvre where the carer bear-hugs the patient and lifts them. In this instance it was to drag the patient up the bed. The harm likely to occur is back injury to the carer and sheering pressure sores for the patient, both of which have negative outcomes. This carer also identified that they were struggling with lack of support in her caring responsibilities, as did another carer. I sought permission from both individuals

to flag up their issues with the relevant services and the drag-lifting with the GP surgery. In both instances it resulted in an increase in community support. I felt this was essential under the category of 'do no harm' and that if I saw risk of harm I would report it, as per the consent form. Other bias risks were possible as I have worked across all settings and am aware of the struggles patients, families and health professionals face during the discharge process. However, I did my best to put preconceptions aside and just concentrate on the data. Grounded theory is a helpful framework for overcoming bias due to its focus on the data and emerging themes. This is evidenced by the fact that I went into the study wondering what the impact on the patient was, but by the time data analysis had finished I had a greater emphasis on the carer, their burden in the discharge process, and how important they are. Focusing on the data enabled me to put my preconceptions aside.

3.8: Ensuring rigour

Lincoln and Guba (1985) theorise that trustworthiness of a qualitative research study is important to evaluating its worth. They suggested that trustworthiness involves establishing the following:

- Credibility – confidence in the 'truth' of the findings
- Transferability – showing that the findings have applicability in other contexts
- Dependability – showing that the findings are consistent and could be repeated
- Confirmability – a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation or interest.

Chiovitti and Piran (2003) developed this further in the sphere of grounded theory. In their study they sought to explicate grounded theory methods and how they can be used to enhance rigour. They found that there were eight methods inherent in grounded theory research practice that enhanced rigour:

> *1. let participants guide the inquiry process; 2. check the theoretical construction generated against participants' meanings of the phenomenon; 3. use participants' actual words in the theory; 4. articulate the researcher's personal views and insights about the phenomenon explored; 5. specify the criteria built into the researcher's thinking; 6. specify how and why participants in the study were selected; 7. delineate the scope of the research; and 8. describe how the literature relates to each category which emerged in the theory.* (Chiovitti & Piran, 2003, p.427)

Finlay (2006) also discussed how qualitative researchers face a challenge to assure quality and trustworthiness and how to not leave themselves open to positivist criticism of subjective and unscientific research. She stated that 'rigour', 'ethical integrity' and 'artistry' are adopted instead of positivist or quantitative criteria of 'reliability', 'validity' and 'generalisability', and that these evaluative criteria must be compatible with the methodology, aims and assumptions. She defined these terms as:

- Reliability – the consistency of the means of data collection
- Validity – the degree to which the research truly measures what it is meant to measure, which presupposes a measurable 'reality' that is undisputed and objective
- Generalisability – ability to extrapolate statistically the findings of a specified sample to the wider population.

There is a concern with how findings can be transferred to other individuals or situations (Finaly, 2006).

Finlay (2006) argues that integrity of the research process and the quality of the end product require evaluation criteria different from these quantitative criteria. The criteria need to allow researchers to 'acknowledge that trust and truths are fragile … [while enabling them] to engage with the messiness and complexity of data interpretations in ways that … reflect the lives of … participants' (Fisher & Savin-Baden, 2002, p.191). Qualitative researchers using explicit criteria are able to claim rigour or critical thoughtfulness. Being clear and explicit about criteria adds to the transparency of the research as well as the researcher's values and interests (Finlay, 2006; Chiviotti & Piran, 2003).

Finlay (2006) makes a case for the 5 Cs: Clarity, Credibility, Contribution, Communicative resonance and Caring. She states that these move beyond rigour to encompass ethical and artistic dimensions and offers a way to move beyond accounting for evidence in terms of scientific criteria, but instead criteria that allow the researcher to address the special qualities of qualitative research – see Table 4. The criteria also help to explore the strengths and weaknesses of the research and to,

> *move beyond criteria focused solely on procedural rigour and confirmability and, instead, apply ethical, literary and creative dimensions. It is these dimensions, after all, that seek to reflect the potential power of qualitative research. The strength and special contribution of qualitative research lies in the way that it can capture the*

richness and ambiguity of the lived experience and the diversity and complexity of the social world. A qualitative study can, and should, be judged on its ability to draw the reader into the researcher's discoveries, allowing the reader to see the worlds of others in new and deeper ways. (Finaly, 2006, p.322)

5Cs	Guidance	How it was implemented in this study
Clarity	Does the research make sense? To what extent is the research systematically worked through, coherent and clearly described?	This chapter has described the methodological framework and the research methods to make transparent the processes involved in the research.
Credibility	To what extent do the findings match the evidence and are they convincing? Auditable? Are the researcher's interpretations plausible and justified? Can readers see what the researcher saw even if they disagree with the conclusions drawn by the researcher?	A coded transcription, case messy map and master messy map examples are included in Appendix 10 to enable auditability and to see how conclusions were drawn. Maps as memos provided an audit trail.
Contribution	To what extent does the research add to debate and knowledge of an issue or aspect of human social life? Does it enrich our understanding of the human condition? Is it empowering and/or growth-enhancing? Does it challenge taken-for-granted assumptions, thereby laying the seeds for potential change? Does it offer guidance for future action or for changing the social world	Outlined in the introduction and literature review are the rationale for the research and the gaps that were identified in the literature. This study adds to the understanding of discharge from hospital of older people living with frailty and takes into account the experiences and perceptions of a range of stakeholders.

	for the better? Does it offer an interesting basis for future research?	Guidance for future practice, policy and research are in the recommendations, Section 6.4.
Communicative resonance	Do the findings resonate with readers' own experience or understandings? As meanings are elicited in an interpersonal context, have the knowledge claims been tested and argued in dialogue with others (including participants, research supervisors and the wider academic community)?	Findings were checked with a PPI group to ensure they resonated (Section 3.8.1). Findings have been presented to lay groups, the school during progression review, external reviewer during end-of-year reviews, and argued with mentor and supervisors at regular supervisions.
Caring	Has the researcher shown respect and sensitivity to participants' safety and needs? To what extent is the researcher reflexive about the way in which meanings are elicited in an interpersonal context? Does the research demonstrate ethical integrity?	Section 3.7.2 outlines how ethical considerations were met and reflexivity about therapist as researcher. Symbolic interactionism and constructivist grounded theory encourage the researcher to be reflexive.

Table 4: How Finlay's (2006) 5Cs were implemented to ensure rigour

3.8.1: Patient and Public Involvement (PPI)

Whilst every effort will be made to ensure the participant voice was foremost, I was unable to purely co-construct with participants during data analysis as I did not have ethical approval to return to participants for anything other than a follow-up, primarily because the frail older patients may have become very unwell or have passed away, and therefore family members may be bereaved. Health professionals are very busy and often struggle to remember a patient once it has been a while since they were last treated. Furthermore, the health system is stretched and I did not want to take up any more valuable time of the health professionals. However, *What is public involvement in research?* (INVOLVE, 2017) defines public involvement in research as 'research being carried out "with" or "by" members of the

public rather than “to”, “about” or “for” them’ (para. 5). This includes advice offered by a steering or special interest group, individuals commenting on and developing research materials, or the undertaking of interviews with research participants. In this study the interview guide, information sheet and consent form were discussed with a PPI group with an interest in end of life issues. They gave recommendations regarding wording, the majority of which was incorporated. As the relationship between the older people living with frailty and their informal carer became a key theme in the data analysis, I returned to the PPI group to check if my findings rang true. In the group there were four women who could identify directly with the carer burden experienced when caring for an older person living with frailty. I spoke to the PPI group again to discuss the conceptual framework and the theory of ‘drive to discharge conveyor belt’. Again, the findings regarding female carer burden rang true for several members of the group, who raised issues regarding advocating for the patient and being relied upon to heavily to facilitate discharge. They also talked about how significant the impact of caring was on their personal lives and feelings of disempowerment. The group has agreed to consult on the lay summary for my study before it is sent to participants who requested a summary during the consent process. The use of constructivist grounded theory included the position central to the methodology that knowledge is co-constructed and the need for the researcher to be aware of the influence they wield in the data collection and analysis. The aim was to privilege the voice of the participants, and, whilst it was not possible to return to them to clarify that the findings reflected their experiences, the PPI group provided a level of co-production by proxy.

3.9: Chapter summary

This chapter has provided a discussion on constructivist grounded theory and the rationale for its choice as a methodology for the study. The chapter has also discussed the study design, recruitment strategy, data collection, data management and data analysis, together with ethical considerations and issues of rigour. The research methods employed were in accordance with constructivist grounded theory, which guided the process of analysis together with the constructivist grounded theory approach of situational analysis (Charmaz, 2014; Clarke et al, 2015). The next chapter presents the findings of the study, together with the categories and theoretical insights which were produced from the data analysis. The substantive theory, which developed from the analysis, is also presented.

Chapter 4: Findings

4.1: Introduction

This chapter presents the findings from the study. Following the principles of constructivist grounded theory (Charmaz, 2014), the core category, categories and subcategories within these are identified. Constant comparison analysis was used to identify constructs in the study. Conceptualisation of the data was derived from 52 participant interviews. Data analysis was a complex process that involved the use of situational analysis messy maps (Clarke et al, 2015), and data was constantly visited and revisited during the data collection and analysis to ensure that emerging categories were grounded in the data.

The core category and the six interrelated conceptual categories and their subcategories, which were produced from the data and formed the basis of the emergent theory, are presented. The relationship between the conceptual categories is examined and made explicit in relation to the construct of this theory. Exemplar participant quotes are used to provide rich descriptions and to contextualise the categories. The participants' quotes have been anonymised and pseudonyms used. Quotes that illustrate how perceived issues may be resolved have also been included so that any recommendations made are grounded in data and constructed by the participant. The discussion chapter (Chapter 5) provides a more extensive engagement with literature and deeper analysis and interpretation.

4.2: Core category, categories, and subcategories

The study aimed to gain greater insight into the specific situation of discharge from hospital in the last six months of life for older people living with frailty. The perspectives of a range of stakeholders were included, in order to come to a deeper understanding of the experiences and processes involved in the discharge. As well as the patient and their informal carer(s), health professionals from the community hospitals and the community were interviewed. Three participants were selected using theoretical sampling. In total 55 participants were interviewed. As this was not a homogenous group of individuals, the core category, categories and subcategories reflect the complexity of issues that surround the discharge from hospital that became evident during the analysis process. Adding to the complexity was the fact that the success of a discharge also appears to rely on events following the discharge. Therefore, the post-discharge experience is also included. Four categories and subcategories were produced from the data. These categories were:

'Resource limitations', 'Mismatch in expectations', 'Choice and control' and 'Carer burden'. The core category that was produced from the analysis in this grounded theory study was conceptualised as 'Drive to discharge conveyor belt'. Themes of trust and communication are woven throughout the categories but were not conceptualised as categories in their own right.

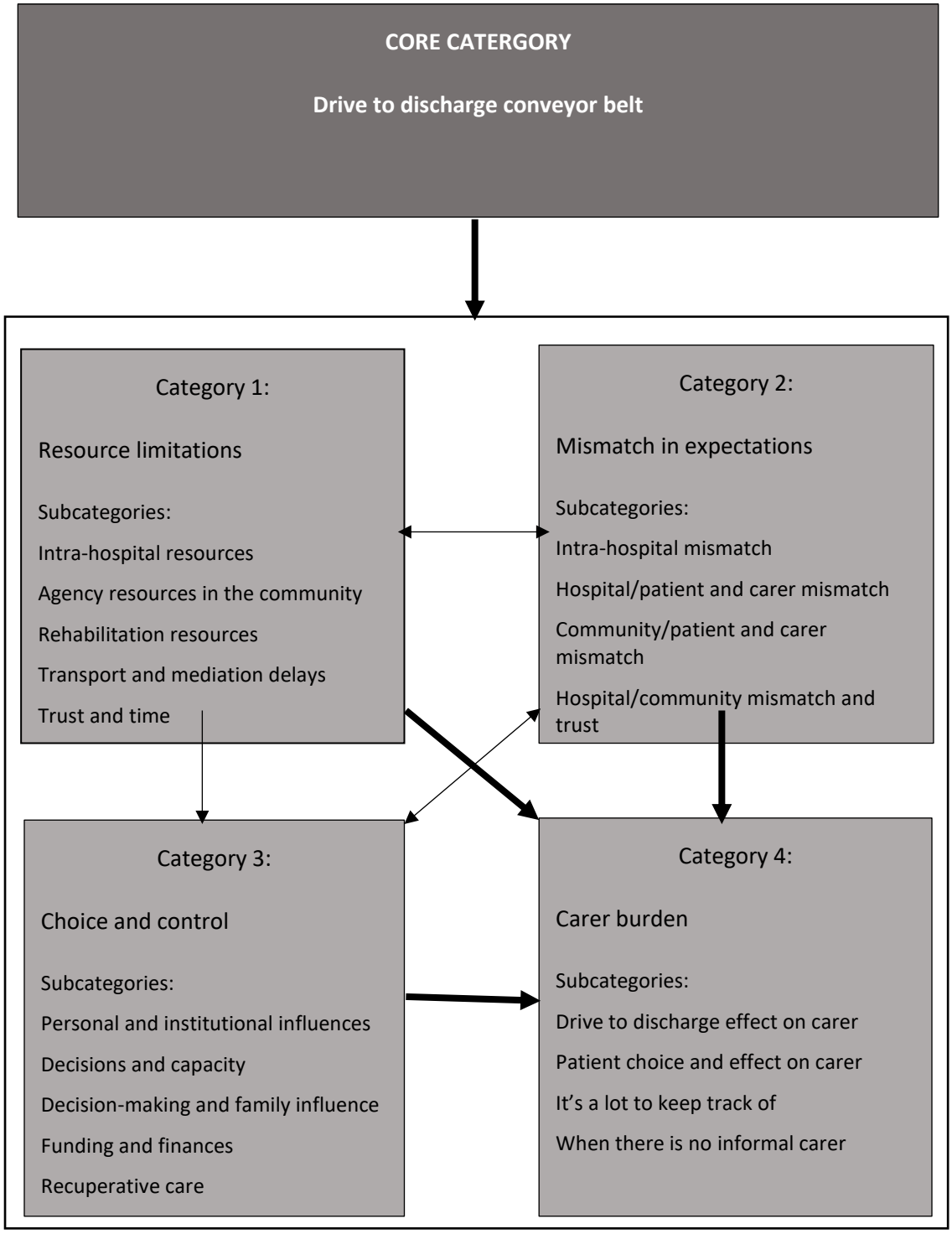


Figure 12: Core category, categories and subcategories

4.3: Participant summary

Initially, patient-participants were identified by health professionals using the question, 'Would you be surprised if the patient were to die in the next six months?' All patient-participants were considered to be living with frailty. Once consent was granted by the patient-participant, their informal carers, hospital health professional and community health professionals were approached to participate. These participants had been involved in the patient's discharge from hospital. Figure 13 is a map of how the participants discussed in the findings relate to the patient and informal carer during the discharge from community hospital. The data in Table 5 is simplified and presented again for the reader due to the complexity of relationships described in the findings.

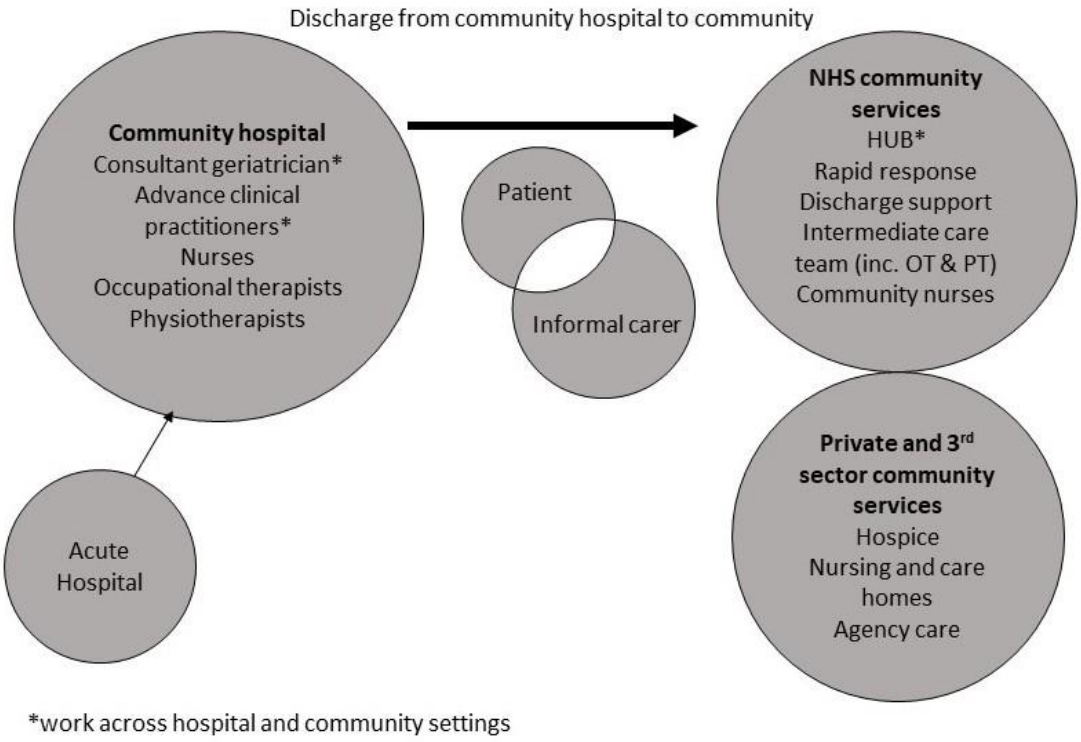


Figure 13: Participant 'map'

Patient	Informal carer(s)	Community hospital health professionals	Community health professionals
Hazel	Brother-in-law Family friend	Nurse Occupational therapist	Care home manager
Amy	Daughter Grand-niece	Occupational therapist Physiotherapist Nurse	Hospice nurse
Alastair	Daughter	Consultant nurse	Nursing home manager
Zoe	Friend Sister	Occupational therapist Nurse	Occupational therapist
Mae	Nil	Physiotherapist Nurse	Physiotherapist Care home manager
Ivy*	Daughter*	Occupational therapist	Rapid response nurse Physiotherapist
Jane	Neighbour	Occupational therapist Physiotherapist Nurse	Frailty nurse
Claire	Niece	Occupational therapist Physiotherapist Nurse	Care homeowner/manager Physiotherapist
Andrew	Daughter Wife	Therapy assistant	Physiotherapist
Iris	Son	Occupational therapist Physiotherapist	Not referred for community support at the time of interviewing
		Consultant Community Geriatrician	Also part of the 'HUB'

Patient	Informal carer(s)	Community hospital health professionals	Community health professionals
			General practitioner
		Therapies lead	

* Interviewed twice: after first and second discharge from hospital.

Table 5: Participant summary

4.4: Category 1: 'Resource limitations'

The first category of 'Resource limitations' was associated with resources within the hospital and in the community after discharge. Limited resources and issues with 'bed blocking' within the acute trust also provided the impetus in the drive to discharge from community hospitals as the system sought to move older people who are awaiting further rehabilitation or social care packages out of the acute hospital and into the community hospitals whilst any issues were resolved. Whilst Ivy was in the acute hospital, her daughter was advised by health professionals that her mother should go to the community hospital. She commented that,

> *they just said she wasn't getting the right amount of attention and care in that [acute] hospital because obviously they were short-staffed and the staff that were there were having to spend more time with the acute patients as opposed to the [cottage] ones.*

The resource issue of staffing is identified as an issue in the acute trust, but is also an issue in the community hospitals. The data also showed issues with resources such as time, ward closures and transport.

4.4.1: Intra-hospital resources

The lack of time to assess and treat patients was causing therapists to compromise their professional values and to reduce their input into multidisciplinary decision making. The consultant geriatrician discussed how her team's intervention had increased the turnover of patients considerably and therefore raised suspicions that the drive to discharge was not for the benefit of patients, but to help relieve acute bed pressures. The drive to discharge and the shortening of the rehabilitation window was having an impact on specific aspects of practice, for example, the occupational therapy home assessment. Whilst the occupational

therapy home assessment is valued by the general practitioner, the therapies lead described a situation where occupational therapists…

> *are not afforded the opportunity to be OT's.*

The general practitioner (GP) said,

> *that's why for me like the OT assessments are quite useful because it's also, is also about what's realistic within the environment that you live, as opposed to not just the equipment you have, but actually, I don't know, it's more than that, isn't it?*

The home assessment enables a hospital therapist to gauge how a patient may perform in the context of their home, rather than in the ward environment, and to put in place appropriate aids and adaptations that will enable a successful discharge. It also informs what transfers and mobilising need to be practised on the ward. Whereas home assessments used to be standard practice, they are no longer as common, not only due to shortening of the rehabilitation window, but also because a community hospital had closed 31 miles away. Therefore, in this case there is a 60–90-minute round trip to carry out home assessments for patients from that locality, which is no longer served by a local community hospital. Distance, combined with time limitations, made home assessments difficult to carry out in the current climate. At one community hospital, an occupational therapist had left because they did not feel valued as a therapist. The therapies lead said,

> *she wasn't able to do the rehab that she had anticipated being able to do when she trained as an OT.*

From this quote, it is evident that the inability to provide rehabilitation and fulfil the therapy role was causing the therapist to feel dissatisfaction with her workplace and with the quality of her work. The drive to discharge with limited staff meant issues were not completely explored. When talking to the consultant geriatrician about Ivy and family issues that were influencing her decision to go into a care home, she said,

> *how often do we have enough time to actually get to the bottom of an issue?*

From a patient perspective, Claire felt that there was a lack of rehabilitation whilst an in-patient. She observed:

> *you need a one-to-one for an hour at a time, but people haven't got the time.*

Claire was discharged after only four physiotherapy interventions during a month-long admission. Once in the community and receiving regular rehabilitation and encouragement

to mobilise she became independently mobile. The lack of physiotherapy input may have been due to lack of staffing resources.

Iris reported staffing issues when trying to get her catheter removed:

> *I think the problem was some of them were quite worried, you know, they were being, you know, couldn't do enough in the time to, you know … I think some of them were overworked, you know. They were lovely staff, you know.*

Iris sensed that staff were 'worried' about what they could achieve during their shift. Issues of staffing and time were also raised regarding community resources.

4.4.2: Agency resources in the community

Once discharged from hospital, formal care can be provided by three different agencies before arriving at the agency that the patient will have long term. The GP said of this situation:

> *What I do hear is a lot of grumblings about the quality of care from people and from families … having multiple different agencies going in, invariably it's, you know, it's confusing, you don't know who's coming in, who's not coming in, families get confused, the communication generally isn't great.*

The GP also described how patients have to fit around the agency resources rather than care fitting around the patient:

> *the carers would not do what they're supposed to do, and they would write into the notes what they'd done, they clearly hadn't done that … which is really sad that they don't plan it to fit around the patient … It's much more about the patient has to fit in with what the care agency can deliver as opposed to the other way around. Which, actually, if you want to facilitate people getting better, you actually need to accommodate them as opposed to the other way.*

The data showed that patients were required to fit with the hospital managerial agenda of quick discharge and then fit into the social care agency agenda of fitting as many people as possible into a short amount of time. The care agencies also have resource issues regarding recruitment, retention and low pay, which is having an effect on how care is delivered. Iris is an example of having to fit around the agency. Iris's son said,

> *the girls that come all right, they're good, they're efficient, they do what they do, it is very good. Timewise, nightmare.*

Iris's son described how he called the agency to request three care calls as he would be unable to help her due to work commitments:

> *On Monday they came at five to 12 to the first visit of the day. I said to the lady that came, I said 'I don't mean this to sound rude but are you the first one of the day or the second one of the day because she should have had one to get her out of bed, one to do her lunch because I'm not here to do her lunch today, and one in the evening time?' The woman said, 'oh well I'm only here for get her out of bed, there isn't three today there's two.' She phoned and they said 'yeah there should be three.' So I said, 'I don't mean to be funny, but I've got to go in two minutes', so I quickly done mum's lunch in the mic and made her a drink, said to the woman, 'I've got to go'. She said, 'oh don't worry, leave it there', so I went and then while I was gone another lady called to do the lunch and the woman said, 'No it's all right, it's been done.' So she then cleared off and just left the one here that done the morning one.*

This quote captures the confusion and stress caused by a chaotic system and illustrates how resources will impact on Category 4: 'Carer burden'. It also shows how patients are expected to remain in bed and without breakfast until midday. Iris and her son gave another example that illustrates how chaotic it is for them to deal with the care agency:

> *no one came, no one came to get her out of bed. So I phoned them up, the woman said 'oh it's been the cock up with the rotas'. No one come to get her out of bed.*

Iris's son said, 'you don't know when they're coming,' and described how this makes it difficult for Iris to attend Age UK. Iris and her son both rate Age UK highly for enabling Iris to get out of the house, for socialising, for personal care such as nails and hair, as well as mobilising around the unit. The centre also does tai chi, which Iris said she found beneficial to her mobility and balance, therefore helping to prevent further falls. The late morning calls are a social care limitation, which is preventing access to this important service. It is also removing Iris's ability to exercise choice and control over her life and the ability to participate in the activities that she finds meaningful. Iris was reluctant to allow her adult son to assist her with washing, dressing and toileting. Illustrated here is also an example of the mismatch between what a community service feels is acceptable and what the patient and carer expect from a service. This will be discussed further in Section 4.5.3: Community/patient and carer mismatch.

The data showed how limitations in the community can lead to readmission to hospital. Ivy's rapid response nurse was asked by her GP to see Ivy with a view to community hospital readmission due to deteriorating health and lack of ability to mobilise or transfer to a commode a few feet away. Ivy's rapid response nurse went to visit and said that,

> *when she stood up out of the chair she was very unsteady and very wobbly and she needed supervision all the time so she's not going to toilet herself on her own in between the three calls a day and at night time especially. I know you can have [an agency] at night but there was no one available and the daughter was actually pushing for readmission.*

Due to the lack of agency availability at night and the fact that Ivy's daughter is already caring for another older person living with frailty in her own home, there was no support for Ivy to remain at home. Ivy's rapid response nurse talked about the closure of recuperative care beds. Recuperative care locally used to be provided at a social services care home, and rehabilitation was provided by social services therapists and latterly by Intermediate Care Team therapists. Patients were over 65 and were expected to return home or make the decision to move permanently to a care home. These beds were either 'step-down' from hospital or 'step-up' to avoid admission. Ivy's rapid response nurse was pointing out that Ivy was appropriate for a recuperative care bed as she did not need any medical treatment beyond some antibiotics, but would have benefited from being somewhere with 24-hour care and supervision, and extra rehabilitation to get her more mobile before going home again. This setting would have also given Ivy the opportunity to see what living in a care home was like. Ivy's rapid response nurse described her perspective of recuperative care closures:

> *She could have gone to a recuperative care bed but we ain't got them anymore, they've taken them away … I feel it's all about saving money, cutting staff, cutting staff, cutting staff, pushing staff, they retire, they don't want to work anymore and where back with … The only reason rapid response works is because everyone is doing overtime, everyone is doing good will, working till 11 o'clock at night when they're supposed to finish at nine.*

Ivy's rapid response nurse talked about the dilemma of deciding whether to admit Ivy back to hospital. Ideally, she would have liked Ivy to go to a recuperative care setting rather than a hospital setting. Recuperative care and its role in decision making is discussed in Section

4.6.5. In the end Ivy was readmitted to hospital because she was deemed not safe at night and the daughter could not stay overnight to help her:

> *I didn't want her to fall again but she could have maybe stayed at home if someone was there overnight help.*

In addition, Ivy's rapid response nurse felt that the lack of district nursing resources may have meant that warning signs were missed. Whilst reading off the shared computer system, Ivy's rapid response nurse was critical of the community nurse input prior to the readmission of Ivy. She felt that their 'task orientated' approach, with '15 visits a day', meant that they did not catch the fact that Ivy had a worsening infection in her legs. When reading from the community nursing notes she said,

> *it's a week later, 'both legs red, swollen and hot to touch, no pain reported. [Ivy] appears clinically well, no signs or symptoms of systemic infection.' Doesn't make sense, to me, that doesn't. Personally, she's got red legs, swollen and hot, I would say cellulitis straight away and she didn't. So if that nurse had gone out and got the antibiotics earlier she may have … We may have prevented hospital admission.*

Ivy was also awaiting community rehabilitation, and her lack of mobility, as well as inability to get into bed, were also contributing factors in her readmission. Ivy's case shows how the culmination of limited resources in the community after discharge can lead to readmission.

4.4.3: Rehabilitation resources in the community

Regarding community rehabilitation, the therapies lead discussed how therapists feel the 'push towards getting home quicker', but that community services are not ready to receive the patient once they are home. The data showed that community rehabilitation did not start for three to four weeks post-discharge. One patient was readmitted in that time. The therapies lead described a common scenario:

> *So what we're actually doing now is getting them to a point where they are safe to return home but not necessarily as good as they could be and this seems to be because of a push towards getting patient's home quicker and then having more rehab within the home environment. What we're finding though, is that the community teams are not able to pick patients up quick enough and we have had situations … over the last year to 18 months, where patients have gone home and we've told them we are going to refer them on, 12 weeks have gone by and their*

phoning saying, 'I haven't seen a physio in the community', and it's just been because waiting times have been horrendous.

The therapies lead blamed primarily the drive to discharge, but also the availability of community and social services resources:

the whole care system, from our perspective, leaving the hospital and going out, is a mess at the moment.

Patients are caught between a hospital system that is driving for discharge and a community system that is ill-equipped to respond to the quick discharges. The drive to discharge combined with the need for older people living with frailty to be seen sooner than four weeks post-discharge is creating a gap in the service that can cause the discharge to fail, or for patients to fail to continue to rehabilitate. The therapies lead was thinking about how the community hospital could help fill this gap:

We're looking at trying to do something whilst the care system that's out there at the moment is in dire straits in terms of our, what's provided for us once they go.

Amy, Zoe, Mae, Ivy, Claire and Iris all experienced a delay in the intermediate care team starting, and Jane experienced a delay in the frailty nurse starting as she was not in post yet. The wait was on average three to four weeks, which potentially negates any progress made during rehabilitation on the ward.

When talking about the transfer of Ivy from hospital back to the community, her rapid response nurse said that she felt the discharge was 'okay' but that the follow-up was not because it took the community physiotherapist two weeks to visit, and then rehabilitation did not start. Ivy's rapid response nurse suggested that it would have been better if the ward had rung the community physiotherapist:

And not an admin, to talk to someone, say we need to hand over and say we need this patient to have rehab within the week please … otherwise they could be waiting three or four [weeks].

In an overlap with Category 2: 'Mismatch in expectations', Ivy was referred by the ward for 'enablement', and this was expected to commence on discharge to prevent readmission. Ivy's ward occupational therapist described the 'enablement team' who are…

> *meant to be enabling independence as opposed to just caring for people so the idea … is that they're encouraging people to be as independent as possible kind of carrying on the assessment and process as well at home.*

However, Ivy's daughter reported that the enablement carers were not doing this role and that in three weeks…

> *since she's been home she's walked once from that chair to her bathroom and back.*

This shows that hospital expectations of what should be happening whilst waiting for community rehabilitation are not being met. Ivy's community physiotherapist suggested that there should be a two or five-day pathway to ensure older people living with frailty are seen soon after discharge, because currently…

> *I mean there is a real emphasis on getting people home but our pathway for rehab doesn't mean we're going to pick them up the next day after they get home, that pathway's not there so it could be a week or two before someone comes out of the cottage and is then picked up for their rehabilitation because there is a waiting list obviously.*

Ivy's community physiotherapist also suggested the ward therapists that have been treating the patient could follow them up two or three days after they have been discharged.

> *They know the patient, they've been working with the patient in the gym, then the therapists outreach into the patient's home for two or three days to work with them on the same goal that they were working with them in the cottage hospital.*

However, Ivy's community physiotherapist conceded that as patients are coming from outside of the immediate locality, due to ward closures, it becomes difficult to do these follow-ups, but she says this would be her 'perfect world'. Ward outreach is also the preferred solution of Ivy's daughter, who said of her mother's care post-discharge:

> *I think they should follow up. I know the world is such a busy place these days but, and I know they say oh, you know, they're so short staffed, but there has to be something.*

Claire's community physiotherapist felt the issues of community resource limitations stemmed from the Clinical Commissioning Group's (CCG) understanding of hospital expectations and community demand, and the subsequent funding issues:

> *We've always asked our CCGs to, when they talk about funding and the amount of time that we see the patients and why aren't we seeing enough patients and we talk about obviously the area that we have to cover, our locality, and we've invited time and time and time again 'come out with us, come and see what we do', never take it up. Or they say they going to take it up, we'll book in a day and then they cancel … We are being very transparent in what we do, all you need to do is come and see it.*

High demand created by the drive to discharge is also found in resources such as transport and medication.

4.4.4: Transport and medication delays

This subcategory is a familiar topic in the literature around discharge. There was one report of medication delay and some transport issues found in the data, illustrating the knock-on effects of a whole system under pressure to discharge and lack of resources to deliver the discharge smoothly.

Hazel and Mae experienced transport delays, and Andrew's daughter had heard about the delays that are possible and opted to drive her father home to avoid delay. Andrew's daughter said,

> *I've got neighbours and I've got friends that have used hospital transport and have to be ready like two/three hours before, I mean what's the point? He's fine in a car.*

Hazel's care home manager talked about the day Hazel arrived, saying that they had been offered a morning or afternoon for the patient to be transported but that the patient had…

> *arrived in the afternoon and I specifically asked for her to be discharged and brought in the morning to give time … To get them settled and they're meant to be booked in, all their paperwork to be done, and quite often we find that they're discharged late.*

This is an example of transport delay and of how resource limitations influence the discharge. According to Hazel's care home manager, there was also a delay waiting for the medication. Hazel's care home manager had asked the community hospital:

> *'Why was her meds and everything not done ready for the morning?' She couldn't give me an answer for that.*

Hazel's care home manager went on to talk about the impact on the patient:

> *They're elderly and they've already been disorientated from being moved to hospital and then being moved to a nursing home, a residential home, it's a big deal for them, you know. So the earlier they get in, the more of the day there is to settle them.*

Hazel's experience shows how traumatic the discharge and transport experience can be for the patient. Hazel's care home manager said that Hazel had arrived at the care home curled up in 'foetal position', tired and exhausted. Furthermore, they said,

> *Her world has completely changed in space of a few weeks from having a stroke, that suddenly changed her life now but it's probably frustrating.*

Mae's care home manager reported that after the discharge:

> *Her first two days here she wasn't very well, but we put that down to the fact that she was in a departure lounge for many hours before she came here and she was tired, and to readjust to being back home again.*

As with Hazel, the return home was traumatic. Mae's care home manager added,

> *We had a phone call to say that she was due, I think, only about 10 o'clock I think … She arrived home at 6:30.*

Mae's community hospital nurse talked about the delay Mae experienced when returning to her care home. She described the transport process:

> *It's not always within the timeframe, that can be a bit of, not very nice for some patients because it gets delayed, they could be hours waiting and it's that anticipation that actually probably one of the processes that is not very good.*

This quote describes the anticipation and uncertainty patients are experiencing at the time of discharge. It also reveals a further lack of control that patients have over their discharge and care. When asked to score the discharge, Mae's ward nurse felt that it was a good discharge apart from the transport letting it down. Mae's care home manager said the good

part of her discharge was that she came home with Do Not Resuscitate paperwork and a 28-day supply of medication.

4.4.5: Trust and time

Whilst there was no single case where the in-patient experience, the transition to the community, post-discharge experience, and experience of the carer were all perfect, there were examples of good practice and successes. These examples of good practice often led to a reduction in carer burden. Amy's case is a good example of how a lot can be achieved in a short admission, as long as the therapists have time to do the appropriate interventions. The occupational therapist provided a lot of reassurance that the patient and daughter could keep asking questions. She made herself available and her practice was transparent. This allowed the patient and daughter to trust the occupational therapist and to work in partnership. As a result, both Amy and her daughter only had positive things to say about their experience in the hospital. Sadly for Amy's daughter, things became a lot more difficult once the Amy was home, which will be discussed further in Section 4.7: Category 4: 'Carer burden'.

When talking about the hospital occupational therapist, Amy called her 'fantastic' and the acute hospital oncologist as 'very professional'. This is in stark contrast to her views on the agency carers post-discharge. During her week-long admission, Amy's hospital physiotherapist and occupational therapist involved Amy and her daughter in discussions and decisions to help alleviate their anxiety regarding the discharge. This involved rehabilitation on the ward with a focus on confidence and anxiety:

> *as she progressed, I think her confidence grew and anxiety lessened.*

The occupational therapist also carried out a discharge home visit, which can be valuable:

> *We did a discharge home visit, which went really well, really well, it reassured her a lot, reduced her anxiety a lot because she was really worried in her mind about how she was going to manage and the home visit was really successful and … she said give it a go and that's what she was saying a couple of days before going, she said 'well, you know, I need to give it a go,' and she was glad that she did give it a go and not go into a care home.*

Amy found this very reassuring and was full of praise for the occupational therapist. Amy said,

> *They didn't just dump and go.*

Amy felt safe and looked after at the time of the discharge. Amy was only in the hospital a week but made quick progress due to the intensive work the occupational therapist did around Amy and her daughter's anxiety. The occupational therapist included Amy's daughter in conversations and admitted that she was 'very intrinsic' in facilitating the discharge to home. The occupational therapist said that she had…

> *a lot of conversations with the daughter because she was very anxious as well and I could see from just her whole body language that she was really emotional and really stressed as well and she also had other family things going on in the background.*

Amy's ward occupational therapist rated the discharge a 10 out of 10, reporting that,

> *both patient and daughter were really anxious and after that they were happy. And she rang the ward, the daughter, the next day saying, yeah, she's happy with the discharge and, you know taking her home. She was very happy so we will take that is pretty good feedback from them.*

Amy's case is an example of how an emphasis on partnership working with transparent and open communication ultimately benefits the patient, their carer and the discharge process in a short time frame. The discharge home visit is a time consuming activity and prevents the occupational therapist from seeing other patients, but the benefits to the patient and discharge were evident and reduced the risk of readmission.

4.4.6: Summary

- Therapies inputs are valuable in facilitating discharge and ensuring that it is successful, but have been limited by pressure to discharge and ward closures. Physiotherapy prior to discharge and the occupational therapy home assessment were found to be key.
- Lack of time equates to a lack of trust.
- The emphasis on shifting patient care to the community requires the resources to shift with the patient in order to maintain patient-centeredness.
- Lack of resources lead to mismatches in expectations.

4.5: Category 2: 'Mismatch in expectations'

The second category of 'Mismatch in expectations' has been alluded to above concerning the mismatch between hospital and community health professionals' expectations of what will happen once a patient is discharged, and between community services and the patient or carer. The category also includes expectations within the community hospital, and between hospital staff and patients and informal carers.

4.5.1: Intra-hospital mismatch

There was evidence that the different focus of management, medical staff and rehabilitation staff created different aims and goals on the ward. This can cause a divide between task-orientated goals that aim for quick discharge and rehabilitation goals with a view to optimum function when returning home. Apparently simple procedures, such as transfer from bed to chair or mobilising to the toilet, illustrate the complexity of the two foci and how they influence practice. The Sara Stedy is a transfer aid that a patient can pull up on into standing, a seat is then pivoted into position behind them. This transfer aid helps those struggling to push up into standing and then step round, for example from bed to chair. However, on the ward the Sara Stedy was being used for quick transfers rather than encouraging standing and stepping round, and was also being used to transport patients across the ward to the toilet instead of encouraging the patient to mobilise. The therapies lead described the different models and the influence on practice as a 'divide between therapies and nursing,' which shows how the different models and their focus can alienate professional groups from each other.

The pressure to perform tasks quickly is illustrated by Hazel's community hospital nurse, who noticed a shortening of the…

> *window [of time to] get them to achieve their, you know, their maximum optimum really, get them to, to be as good as they can before they leave …you're given very little time. When you think sometimes if patients were with you a little bit longer they may have, be able to achieve much more and I know some people do go on to go home and have ICT and carry on that process but we also see patients that go home and are waiting for ICT and because of the waiting time for ICT they tend to deteriorate and end up going back in.*

This was the case for Ivy, who was readmitted twice, and both times before the community rehabilitation commenced. Ivy's daughter talked about her mother's care at the community

hospital and remarked that nursing staff 'chucked her' on the Sara Stedy, which suggests a perceived lack of care in the moving and handling of her mother when the task is more important than the person. She also queried whether the fact her mother was reliant on a transfer aid suggested that she was not ready to be discharged home where she cannot transfer to the toilet until a carer visits, and whether she was 'fit enough to go home' as the use of the Sara Stedy is not enabling independence as staff have 'chucked her on that for speed, for quickness'.

The shortening of the window of rehabilitation was concerning hospital therapists who queried whether the community hospitals are providing rehabilitation any more, or whether the drive to discharge is more important. For example, the therapies lead said,

> *We are still being told that we are rehab hospitals and that we should be providing rehab for patients, however what we're finding is that patients are coming in and being discharged, sometimes the next day, sometimes within a few days, sometimes a little bit longer, but essentially, whereas we used to have an 18 or 21 day work period, we are working often that the patient will come in and go straight away, and you can't rehab someone to their baseline.*

The therapists are receiving mixed messages that they are to rehabilitate patients but also discharge them as soon as possible, which is causing a mismatch in expectations. Whilst Hazel's ward nurse felt the window to rehabilitate was getting shorter, she equally did not condone the 'blanket' six-week rehabilitation that used to be in place:

> *I don't think it should be a blanket, it should be individual to that person and what they want to achieve and, you know what as a team we think is achievable.*

Recommended here are patient-centred goals and multidisciplinary decisions made with the patient, with the use of health professionals' clinical reasoning. However, the therapies lead talked about the impact of the lack of communication combined with the drive to discharge quickly on patients, family and therapists:

> *Recently we've noted here that the frailty team, and in particular the consultant, have been a ward round suggesting to patients that they are going to go home the next day without really discussing that with the therapists in particular … The OTs in particular have phoned up relatives to say, 'your mum, your dad, whoever, is going home tomorrow', and then she's actually been bombarded by quite angry relatives because it sort of come out of the blue little bit … The opportunity is not any longer*

there, they might do an assessment but it's almost like a tick box now, because they know they're not going to have time to redo it.

The impact of the drive to discharge and the shortening rehabilitation window is evident in this quote, but also described here is a lack of communication between professions where the medical model overrides the therapy model in the decision-making process. Finally, it also shows how a mismatch between the hospital, patients and their families can be created.

4.5.2: Hospital/patient or carer mismatch

The mismatch between hospital expectations and patient/carer expectations is best illustrated by Alastair, Claire and Andrew's cases, where the mismatch created carer burden and loss of trust.

Alastair experienced four admissions in a nine-month period, which included acute and community hospitals. During his third admission he was diagnosed with a brain tumour. His daughter tried to voice concerns regarding the drive to discharge Alastair back to his home, given the previous two failed discharges and his worsening health:

we kind of had a worrying conversation that they were claiming he was independent and I said 'he's not'.

She continued,

They were wanting to send him home even though he hadn't been able to use his legs for two weeks and he was going round in a wheelchair and how he live in a first floor flat and he needs to climb fifteen stairs … they were determined to send him home.

The drive to discharge led to Alastair's daughter feeling helpless in the face of the push to discharge her father home rather than to a care home. After the interview she asked to see me without her father in the room. She showed me pictures she had taken of his home environment to use as proof that he was not capable of looking after himself; neither had he been looked after in the community. She said,

when we ever asked that 'we don't want him to go home', it was just a constant 'no'.

There was a distinct mismatch in what Alastair's daughter thought was an acceptable discharge destination; also in question was her father's capacity or insight to make decisions about his own care needs. During the third admission there were a lot of conversations

regarding Alastair's capacity and his desire to be independent. There was a clear mismatch around the subject of capacity. The mismatch in expectations also continued on into the community setting. Clear communication resulted in reduced mismatch and regained trust. Alastair's daughter described the bad experiences during three hospital admissions. She was very distressed and felt she had a terrible experience during the previous three admissions. However, the fourth discharge was when I met them and they had finally had a good experience. Alastair's consultant nurse helped coordinate the discharge and is an example of good practice making a good discharge through honesty, transparency, partnership working and open communication:

> *I phoned his daughter and said to her, you know, 'I understand that you made a complaint and I don't want to know anything about it. I just want to say that I wanted to start off on the right footing and be open and honest with each other, and if there are any concerns that you talk to me about them if you have them and I'll talk to you if you have them and we'll try and get your father to where he wants to be or the best place for him.'*

The family were happy with this discharge and it significantly reduced the burden on Alastair's daughter.

Ivy and Andrew's cases demonstrate a mismatch and how trust and faith in health services can be lost through poor communication. Firstly, Ivy's daughter said the discharge was 'all of a sudden', which suggests a lack of communication in the build-up to the discharge. Ivy's daughter did not feel assertive enough to request more rehabilitation before her mother returned home.

> ***Ivy:*** *…when all of a sudden they said I was going home on the Friday didn't they?*
>
> ***Ivy's daughter:*** *So I was like 'oh right, okay', you know. And to be honest with you because she was so much brighter in herself I possibly, I should have said I'm not happy about it but I didn't and I could kick myself now and, but then I didn't know if that would have made any difference, if I'd have sort of said, you know 'can you keep her in longer? I don't feel she's ready'. I did keep sort of saying to them, you know 'oh how is the, you know, walking.' 'Oh yeah, well we've had her do this and, you know, a couple of times and whatever' and they were brilliant in there, they were so, so nice and you don't like to sort of upset anybody, which is probably not the right thing to do.*

In the face of the drive to discharge, Ivy's daughter felt powerless to say that she did not think her mother would cope at home and needed to be more mobile prior to discharge. The community physiotherapist visited two weeks later but did not commence rehabilitation. On the day I visited, Ivy was unable to stand from her chair and the GP arrived at the end of the interview. Later that day the rapid response nurse readmitted Ivy to the community hospital. I interviewed Ivy and her daughter after this failed discharge. Ivy's daughter said,

> *You put your faith in them that they're saying, you know, when they're saying that she is ready to come home, you're like 'okay fine, if that's the case.'*

Despite her worries, Ivy's daughter trusted that decisions were being made in her mother's best interests.

Andrew was a different example of communication issues between ward staff and the carer having an impact on the discharge and the post-discharge experience. Following a fall and fractured vertebrae in his neck, Andrew needed to wear a collar to prevent further damage and paralysis. On the ward, staff had a lack of experience with collars, which meant that Andrew's daughter and wife were not shown the correct way to care for Andrew when washing and shaving. Andrew's community physiotherapist criticised the lack of support in hospital prior to going home:

> *It was like here's this book [the collar instructions], go and read it, go and work your own way out of doing it and they've ended up adapting probably, you know, not the safest of ways. But they've done what you know, they've done what they thought was best and then didn't like, you know, it was just after, I think me coming in was after the horse has bolted so I was not gonna win … It was almost like a right, you know, it's too late now, you can come and show us if you want.*

The poor communication and scant provision of accurate information in the hospital influenced the post-discharge communication with community services. By the time the community physiotherapist made contact with Andrew's daughter, all communication had shut down due to loss of faith and trust in health services. Andrew's daughter did not engage with the community physiotherapist's advice regarding collar use and she chose to continue to use her self-taught methods, effectively removing her father from the system.

There was a mismatch between hospital and carer perceptions of an appropriate discharge destination in the case of Claire. However, rather than removing her aunt from the system, Claire's niece pushed back against the drive to discharge until a discharge destination she

felt was appropriate was found. This case is discussed in more detail in Section 4.7 on Category 4: 'Carer burden', since resisting the drive to discharge creates a burden. The mismatch could have been lessened through accurate information as a delay was caused by nursing staff telling Claire's niece to find a nursing home, when in fact a care home was required. When Claire's niece realised that it was a care home she should be looking for she found one quickly.

4.5.3: Community/patient or carer mismatch

Returning to Alastair, his daughter was disappointed with the community care her father received in between his multiple admissions. As she did not live nearby, she was relying on community services to flag up issues her father may be having in order to prevent distress, harm and hospital admission. She was critical of the level of care and felt that if the community nurses had provided more care her father would not have been admitted for sepsis, which was the cause of the second of the admissions:

> *he then got sepsis in his legs because they weren't begin dressed regularly enough. And he was sat with saturated dressings, a puddle on the floor of, well, whatever's coming out I guess, the fluid that was coming out of his legs and he was left like that for weeks. So then he went back to hospital with pressure wounds and the sepsis.*

After the second admission Alastair was assessed in the community for care again but his daughter was told that despite his vascular dementia and lack of ability to care for himself the assessor said,

> *he needs to ask for help to receive help.*

Alastair's daughter lived over an hour's drive away and was getting shopping delivered, but reported that when she visited her father she found that the carers had been…

> *stepping over the shopping that was on the floor and it was left to rot and he hadn't eaten for three weeks, and that was never picked up on.*

Then Alastair got sepsis again and was in so much pain he was taking paracetamol and was readmitted due to…

> *an overdose, a staggered overdose of paracetamol because he had no carers there to look after him. They were coming in and signing the book, weren't they? And saying that they'd cared for him but actually they hadn't done anything for him. And he was asking his neighbour because he was screaming out in agony if he could get*

him some paracetamol and he was, on top of the other medication he was taking, so he was taking these paracetamols and he's effectively had a staggered overdose which affected his kidneys.

From these quotes it is clear that Alastair's daughter is attempting to look after her father and hold his community care together from a distance. This feeds in quite plainly to the carer burden category. Alastair's daughter described how she felt let down by the community nursing input her father was receiving in between multiple admissions:

They were due to come in three days a week, sometime would be twice a week, sometimes it would be Monday, then it would be a Friday, so it's a long period in between, then his pyjamas were stuck to his legs when they'd come in. But that's the other thing I felt really let down, that they'd not let anyone know that it's not right he's living like that.

These quotes show a mismatch between Alastair's daughter and community services. She expected a certain level of care that involved regular and consistent interventions, and for concerns to be flagged to herself or relevant agencies to prevent further health deterioration, harm or hospital admissions. After the fourth admission, Alastair was admitted to a nursing home. His daughter commented on the difference between the care Alastair had been receiving in the community and the hospitals in the previous nine months, compared to the nursing home:

They're amazing here … It's such a different care, level of care, it's unbelievable.

And the staff, she said,

speak to him like a human.

Alastair also observed:

it's a lovely thing to be out of pain.

The relief that their trial was over and that Alastair was now safe, well looked after, in no pain, his legs were healing and everything would be calm as he reached the end of life was clear. Trust had been restored during the fourth and final admission as they felt listened to. Trust was also regained at the nursing home as Alastair's needs were taken care of and he was out of pain.

Further examples of a mismatch between the community services and patient or carer expectations can be found with Ivy. Ivy's daughter described how there was no consistency

in the carers, and the difference it makes having a carer who knows her mother and who has a good routine:

> *Because [XXX] does mum Monday to Friday she's got into a lovely routine, a great pattern with mum she knows mum really well and, you know, she's got her routine, you know, she'll come in 'right come on, let's get you sorted' and then perhaps mum says 'oh I need to go to the toilet', so whilst she is sitting on the toilet [XXX] will go out, wash up what has been left from the night before. Feed the ca t… She's not just standing there, she will make use of the time … If they were consistent, they would have that nice pattern and they would you know, things would settle in better.*

The unsettled nature of the formal care input creates carer burden, as seen in Section 4.7.4: 'It's a lot to keep track of'. Also, Jane when talking about care agency staff not using the bedpan provided said,

> *Everything is down to them, easier for them, and I've got to suffer.*

Jane was very unhappy about the time at which care agency staff arrived in the morning saying,

> *They should be here at six, come here at ten.*

Whilst 6 am is a little early for an agency carer to arrive, it is understandable that someone who is unable to change her position in the bed, and unable to get out of bed, would be eager for a care call earlier than 10 am. Jane was vocal about her dislike of hospital staff and agency staff; the only person she seemed to appreciate was her neighbour. Jane relied heavily on her neighbour to supplement the four double-handed care calls the hospital had put in place. During the interview Jane's neighbour was desperate for some help. This will be discussed further in Section 4.7: Category 4: 'Carer burden'.

4.5.4: Hospital/Community mismatch

The data showed a mismatch in what community hospital staff thought would happen after discharge and what community staff and agencies feel is appropriate post-discharge. Additionally, community staff were critical of the work done in the hospital due to a suspicion that hospital staff are prioritising discharge and cutting corners; this resulted in a loss of trust between the two settings. Zoe's case illustrated this mismatch well, whilst also highlighting communication, resource and carer burden issues. At the time of discharge,

Zoe's hospital occupational therapist had initiated community services, via the 'HUB' but also Age UK to support Zoe and her sister, who lived together.

Zoe was in her nineties and her sister was in her eighties; her sister was also experiencing increasing frailty due to undiagnosed health conditions. The hospital occupational therapist rationalised that…

> *It is far too much for one person and that's why hopefully with the other services that we signposted to, that they can take on some of that, like Age UK, they've got a care navigator service and someone can work with them over a long, you know, longer period of time.*

The hospital occupational therapist also explained that the care navigator was also useful:

> *Because the sister mentioned finances a few times as well, so I got the feeling that that might have been an issue but I don't know if they were getting all the benefits they were entitled to, so the care navigator would have looked at that as well.*

Zoe's consultant nurse also referred to the 'HUB'. She stated she did this because she…

> *wanted the community to know that [Zoe] was going home and that she would be vulnerable and we would be referring her to specific teams like the intermediate care team.*

Zoe's consultant nurse discovered that because Zoe and her sister had never had contact with social services before, there was a delay in services commencing. Post-discharge there would be three different services providing care before settling to the permanent agency. It is a complicated system for the sisters, who had never dealt with the health or social care system before. As finances were a common theme in conversation, it seemed health professionals were concerned that the sisters may cancel any care package if they were required to pay for it or if things became complicated. The greatest fear was that they would become even more vulnerable without sufficient support in the community.

Talking about the limitations of what can be done in the hospital before moving to the community, Zoe's hospital occupational therapist said,

> *I just felt as if we could have done more with the bungalow but, you know, it's not something that can be done quickly. But I couldn't think of anything else I could have done but I felt like it still wasn't perfect, it was still an environment that wasn't great*

but they were living like that for a long time but obviously it came to our attention and then, you know we had to.

Here the hospital occupational therapist is acknowledging that prior to her fall Zoe had been living in that environment for a long time. She was attempting not to place too much of a value judgement on what is considered an acceptable way to live, whilst taking steps to try to ensure Zoe was safe in that environment. A referral was made to the Intermediate Care Team. Zoe's community occupational therapist visited the sisters and immediately tried to readmit Zoe back to a community hospital because, they said, the…

Home environment is awful.

This demonstrated a difference in what living environments are deemed acceptable. Zoe's community occupational therapist said she wanted to readmit Zoe to the community hospital due to lack of action in the community:

I wanted Urgent Care to go out and put her in a place of safety, if Social Services weren't going to do anything, or the GP wasn't going to do anything, because I requested the GP to go out as well, she went out but the sister wouldn't allow access to her, so she just basically done a very brief report, she didn't even look at [Zoe], she thought I wanted her to look [Zoe's sister] but I didn't, I wanted her to look at both of them.

Social services had not provided any input by the time the community occupational therapist first visited. Communication between the community occupational therapist and the GP was lacking. When I asked why she felt readmission was necessary, the community occupational therapist said that she wanted Zoe to be in a…

place of safety where she could improve her mobility … so that she could be well-nourished, because she's 5 stone, she's lost 2 pounds since she's, 2 pounds in two weeks she's lost.

This illustrated another area of mismatch related to the reality of providing rehabilitation in the home environment. Zoe's home was cluttered due to hoarding and dirty due to the dog that was no longer being walked. This was not conducive to improving mobility and transfers. There was also evidence that an already malnourished Zoe was losing weight because her sister was unable to cope with the caring responsibilities in the face of her own deteriorating physical and mental health:

She was hungry, so I went and bought her some food, the sister wasn't too pleased that we had taken the food, but [Zoe] was really pleased that we had, because she kept saying that she was hungry.

For the discharge to succeed there was a reliance on an informal carer, who was not able to do what was needed in order to care for the patient sufficiently. The sisters had a family friend who was increasingly relied upon from the time of Zoe's admission until the sisters' death. Their friend, a retired nurse, was seeking help from community services but found that Age UK refused to support the sisters due to the dirty and cluttered home environment. The community occupational therapist was then the third person to refer to the 'HUB'. Zoe's community occupational therapist was critical of the hospital occupational therapist and scored the discharge 4/10, compared to the hospital occupational therapist who scored it 8/10. The community occupational therapist said this was…

because the OT had been in before, so she had seen obviously the home environment, she done a home visit to look where hospital bed and commode could go, obviously didn't take any consideration into the home environment in any other respect because obviously I would have flagged that up with social services a bit earlier on really.

The community occupational therapist had assumed that the hospital occupational therapist had not done her job and felt strongly that the patient was not safe to be at home and that the home environment was not suitable for community rehabilitation. The community occupational therapist made referrals to the same services that the hospital occupational therapist had already made referrals to, and the patient was also known to the 'HUB'. However, she was correct that there was not sufficient support as services had not been initiated by social services or Age UK.

The consultant nurse was alerted to the fact that support had not gone into the sisters due to community occupational therapist's referral to the 'HUB':

I was a little annoyed because I'd already done that and I would have expected the actions that were necessary to have come out of my initial referral, so for it to come back and still be a problem, you know, is that because this is like insoluble and the systems that we have don't have a resolution to problems like that? You know, that's very sad if as the seventh richest country in the world whatever we can't look after two frail old ladies.

As a community practitioner, the community occupational therapist saw the patient living in their environment two or three weeks after discharge and could see more clearly the risks and hazards that may not be apparent from the hospital. There was a clear mismatch between the community occupational therapist trying to readmit Zoe on the grounds of safety in the absence of community support, whereas the hospital staff were trying to mobilise community services to avoid hospital admission. All parties want what is best for the patient, but the community occupational therapist did not feel the pressure of the drive to discharge as ward staff did.

The Sara Stedy has been discussed above concerning the difference in focus between nursing staff and therapies. Ivy's rapid response nurse was also critical of practices on the ward that were perceived to be corner-cutting and not preparing the patient to return to living alone in the community. Ivy's rapid response nurse criticised the overuse of a transfer aid called a Sara Stedy:

> *People will do things for the patients because it's quicker. Everything is quicker so the healthcare assistants will assist and will do everything … If they're on a Sara Stedy they're not rehabable, are they? Why are they on a Sara Stedy, they're going on a bloomin' hoist after that.*

She is alluding to the fact that misuse of the Sara Stedy will not only prevent rehabilitation but is disabling and will lead to the need for full body hoisting. Ivy's rapid response nurse worked in the community and was under the assumption that the community hospital beds were for rehabilitation. Whilst reading from the shared computer system she highlighted the issue of language regarding 'rehabilitation' verses 'medically fit' for discharge, which made her suspicious that rehabilitation was not being provided in the hospitals:

> *The beds are for rehab, medically stable is the acute … a cottage hospital is a rehabilitation ward for people who are more at risk who can't go home to rehab.*

She expanded on this topic in relation to the impact it has on community staff and the patient once they are discharged. She goes on to suggest how the issue could be remedied:

> *That means that we're actually doing someone else's job because the rehab hospital should be making sure these patients are medically stable to go home and they can actually rehab properly, you know, if they think that in two weeks they're going to go backwards and they shouldn't be discharging. Or maybe those phone calls do need to happen. That communication from the cottage hospital to rehab needs to*

happen to say we need to have this patient seen within a week please of discharge or next few days if they can't.

'Doing someone else's job' suggests a lack of trust or respect for the work being done in the community hospitals and the nursing care as the drive to discharge sets up conflict between settings.

Whilst talking about the speed at which patients are discharged, Ivy's rapid response nurse was critical at the length of time it took before rehabilitation commenced:

Nearly a week went by before they rehabbed her on the ward. That's so bad. … I think they need to do more rehab on the ward than they are.

Claire's community physiotherapist was also critical of the rehabilitation input on the ward, and again, the use of the Sara Stedy. The ward physiotherapist did not refer Claire for community rehabilitation; this was left to the care home manager, who stated,

The hospital said that they, they considered the physio input to be finished, that their, her ability at that moment was, you know, what I guess they would most expect her to achieve.

Claire's community physiotherapist encouraged care home staff to help Claire to walk more and to do step round transfers as much as possible, without the Sara Stedy. The care home was supportive and Claire became mobile. Whilst this is an example of how rehabilitation can be carried on in the community, the community physiotherapist was querying why this level of mobility was not achieved in the hospital before being discharged. Had Claire been this mobile on the ward, she would have been able to go straight home instead of to a care home. Considering Claire's admission was longer than usual, her community physiotherapist queried why ward therapists had not achieved full mobility before discharge:

Considering she's been in there for quite some time and not achieved her potential before she went out, I would like to question why she didn't reach her potential. When I went and saw her once, within a couple of weeks she's up, she's walking, she's, you know, so it would, does beg the question how much encouragement, how often was she seen, you know, there are all of these questions that need to come into play, you know, was she seen just once a week, once every couple of days, because somebody like that needs to be seen two, maybe three times a day to get them up, get them walking, get them motivated, and evidence shows that, so if that's not happening, and that encouragement isn't there

In this case, the patient was not discharged quickly, but perhaps due to the short rehabilitation window for patients on the rest of the ward, it explained why the ward physiotherapist had only four interactions during the admission. It also showed what physiotherapists may consider the gold standard for providing rehabilitation, which is two to three times a day, every day. However, Claire's ward physiotherapist said,

> *We just transfer them home with the equipment irrespective of whether they're mobilising because we have to get people out fast, that's how it is now.*

On the one hand, Claire's case supports the medical narrative that rehabilitation can be done in the community, in a care home setting. However, it also shows that with the right support Claire was capable of making progress quickly, and therefore this could have been achieved during her long admission if staff were available to provide the necessary input, which is an overlap with Category 1: 'Resource limitations'. Furthermore, if rehabilitation is to happen in the community, a referral needs to be made at the time of discharge to prevent delay and for comprehensive handover of care. The 'them and us' rhetoric is indicative of silo working.

4.5.5: Reducing silo working

Claire's community physiotherapist gave an example of a practice that is reducing the mismatch between hospital and community staff and silo working, which is the 'HUB'. Claire's community physiotherapist stated that she found the 'HUB' meetings positive, enjoyable and productive. She found the 'HUB' to be…

> *very approachable … and nothing you ask them is deemed as silly, it can be the slightest little thing and it's having an appreciation for what each individual can do for that patient. So you're working far more collaboratively and you are working for that patient-centred approach that they keep going on about they keep banging on about.*

The 'HUB' fosters trust and encourages communication between services, with a focus on the patient's best interests. It also reduces repetition of referrals and work. For example, Zoe's community occupational therapist was critical of a perceived lack of hospital occupational therapy input. This may have been exacerbated by the limited information provided in the referral form. The community occupational therapist felt that the referral was lacking in information which had been requested to 'promote mobility'. Zoe's community occupational therapist stated that the team would have liked a bit more information about the home environment and hazards. It may have also helped if the

hospital occupational therapist had provided more detail regarding the measures she had taken to make the home environment as safe as possible. For example, the hospital occupational therapist had worked with Zoe's family friend to de-clutter and clean and had provided equipment.

Silo working occurs when groups do not share information. The main form of information communication between the hospital and community services at the time of discharge is the discharge letter and referral letter or referral form. The discharge summary communicates the details of the hospital admission and medication and is intended for the patient and their GP. The referral letter and referral form are used by the hospital to request community services that are required after the patient is discharged. This includes services such as community nursing, community rehabilitation (Intermediate Care Team), hospice nurses, dietetics, cardiac rehabilitation and pulmonary rehabilitation. Referrals are also made to social services for care and support in the community. In their study of referral letters, Jiwa et al (2004) found that there was a 'paucity of information' in referral letters. The data also found this to be the case. Hazel's care home manager detailed the process a care home goes through before accepting a patient. She said they ask 'to see all the information' in order to gauge if the patient is appropriate for the care home. However, Claire's care home manager has found that relying on a referral letter means that key information is missing and therefore it is necessary to read through the patient notes on the ward:

> *It's no disrespect to them because they're very busy in hospitals but you may not get a key piece of information, that by reading all the notes you pick up on everything because you've had that chance to sit and read what's been going on from the minute they've been admitted.*

There is a lack of trust that all information will be relayed and that the hospital cannot be relied upon for accurate information, which exacerbates the mismatch and reduces trust in the hospital as it appears they are omitting information in order to speed up the discharge. Information such as the patient's mobility, ability to feed themselves or continence are examples of information care homes need in order to decide if their home is appropriate and they have the staff available to provide the level of care needed. When talking about the need for reading the patient's hospital notes in-depth as referrals can sometimes be inaccurate she remarked,

> *things you read on the paperwork don't always match the patient.*

Hazel provides an example of how a lack of communication from the hospital to the care home has a significant impact on the patient. There appeared to be a lack of guidance regarding care of pressure sores. The care home manager was keen for the patient to be sat out in the lounge with the other residents saying,

> *I don't see the real difference, unless she was really at risk of breaking down and needed to be on an airflow mattress constantly, constantly turned, but she's been downstairs, she sat in a recliner chair and she's interacting and seeing what's going on, rather than be in the bedroom where there's nothing going on because she's not in a communal place to see.*

However, in hospital Hazel was nursed on an airflow mattress due to the high risk of pressure sore breakdown. When contacted a month later, Hazel's care home manager reported that the pressure sores had opened up and that the patient was now considered end of life. Hazel's information had not been transferred to the community nurses either. Hazel's care home manager reported that the community nurses had not been informed of Hazel's arrival in their area and that she had a catheter in situ that needed changing.

Amy's community hospice nurse and Mae's community physiotherapist were also critical of information provided on the referral form. They both commented on how a lack of information caused extra work in finding out enough about the patient otherwise you risk 'going in a bit blind', as Amy's hospice nurse said. Mae's community physiotherapist was unable to make informed decisions with limited information and that with clearer information Mae might have been seen sooner:

> *So this could have been dealt with a bit more earlier if you liaise properly, I mean if, I would expect a physio to you know to discuss with me maybe over the phone, something, 'Okay I'm discharging [Mae], she has made good improvement with us, could you please see and just as soon as you can and just continue with the plan?'*

A clear and informative referral can prevent the doubling up of work and wasting of time:

> *so we don't need to do that all over again … I believe to just make a quick bridge, or just passing someone to different care and just working from their rather than taking the whole circle back again.*

Instead of starting all over again with assessment in the community, Mae's community therapist is suggesting that the rehabilitation should just carry on from the work done in the hospital. This is only possible with a detailed handover and trust between hospital and

community physiotherapists. Mae's community physiotherapist talked about how she felt that other services 'just pass the buck' when they are not quite sure what to do with patients whose mobility keeps deteriorating. This creates a lack of trust and the feeling that the service is being abused and not respected. Claire's community physiotherapist also found it disrespectful when referral forms were inadequately completed with patient details:

> *I mean there's a section there for it, they're just not filled in. And I, I have to say I find it disrespectful in some respects because they've got no respect for the fact that we are having to go out and see the patient in the community with a name and address and 'Improve their mobility.' If you want to find out any information you have to ring the ward, you end up speaking to the ward clerk who then has to find out who the physio was, who then says 'oh, they're not here at the moment, get them to ring you back', they don't ring you back.*

There also appeared to be an issue of trust regarding when the hospital thought the hospice nurse might visit Amy as they said on the referral form that the referral was 'urgent' when it was not. Amy's hospice nurse reflected,

> *I sometimes wonder if they don't understand what we do, so therefore they put urgent, and or also they're worrying that we won't respond, but we respond to referrals quite quickly.*

This possibly suggests a lack of trust on the part of the hospital that the hospice will see the patient in a reasonable amount of time. Amy's community hospice nurse found an oncology letter on the computer system, which she found more informative and described in more detail the patient's history of breast cancer and that her issues currently were more related to overall frailty and a fall. Amy's community hospice nurse said is 'was actually more useful than the referral' as the referral was 'a bit vague' and 'not worth the bit a paper it's written on'. She stated that ideally a referral would include more information:

> *from a professional to professional point of view it would be useful to know what they really want.*

As the hospital staff know the patient well they would ideally pass on accurate information and be clear about what they would like the community service to do, thus saving time and confusion but also fostering trust and partnership working whilst reducing the mismatch in expectations and silo working, whilst benefiting the discharge process.

4.5.6: Summary

- There appears to be a lack of communication to staff and the community trust regarding the vision for what the community hospital goals and priorities are, which causes a loss of trust between services and staff and fosters silo working.
- There also appears to be a lack of communication of what the community hospital envisions which services the patients will receive once discharged and how soon these services will start post-discharge.
- The HUB was identified as a good multidisciplinary group that reduced silo working and improved information sharing. Improved communication through referral letters would increase transparency and trust whilst reducing silo working.

4.6: Category 3: 'Choice and control'

This category considers the drive to discharge and its impact on individual experience in the face of rhetoric of choice and control, as well as how choice interacts with the drive to discharge and how decisions were made.

4.6.1: Personal and institutional influences on choice and control

The first subcategory of 'Choice and control' is related to the power of the drive to discharge and the impact it has on a patient's choice and control. The subcategory also includes challenges to the rhetoric that 'home is best' and that rehabilitation can continue successfully in the community rather than in a ward environment. People are complex and make choices based on different things that are important to them such as pets, social isolation and so on.

Iris had a son living in her home, but she did not feel confident to return home. She asked to stay in the hospital for more rehabilitation before being discharged.

> ***Iris:*** *I'm willing to go home but I don't feel confident enough to go home. And so they said 'we'll keep you a bit longer'. That's all they said.*
>
> ***Me:*** *But then you went…?*
>
> ***Iris:*** *Next day.*

However, Iris was discharged the next day, and when she voiced her concerns she received a rather dismissive response:

> *Well I was a bit nervous coming home, you know, but he said 'Oh it will be by a proper ambulance, you know, nothing to worry about.'*

Iris was not concerned about her mode of transport, she was worrying about how she would cope at home. The drive to discharge is overriding patient concerns and she was given false hope that her admission may be extended by a day to increase her confidence and get more rehabilitation. The case of Iris also provides an example of poor communication between hospital and community, as well as with her son. Iris was referred for outpatient physiotherapy rather than community physiotherapy, when she could not mobilise out of her front door, despite her son trying to flag the issue. Iris believed that she had exercised some choice and control over her discharge, but ultimately was discharged on the date that had been set. Iris's hospital occupational therapist said that Iris had been 'apprehensive' about going home but that during previous admissions she had done home visits with Iris:

> *I just felt like I didn't really need to do one with her this time but maybe it would have reassured her a bit. That's why I said well I'll come and do a follow up, well bring the commode, because we could have just got it delivered … but I think she felt she needed more time but she didn't because she had been here for a long time.*

Owing to the drive to discharge, there was not enough time to be able to provide sufficient reassurance. Iris went into more detail about the communication process around her discharge:

> *When I was coming home the day previous and they came and said to me 'yeah, what do you think about it?' I said 'well I think I want a few more days.' They said 'Well you get hospitalised and you never will go home.'*

When Iris said 'hospitalised', she is referring to institutionalisation, which is a rationale for discharging quickly and is an overlap with Section 4.5.2: Mismatch between hospital and patient expectations of how mobile and confident you should be to go home. The policy and managerial focus that home is best is not necessarily true for older people who are immobile or lacking in confidence. The home is best rhetoric also fails to take into account social isolation, which for Iris was exacerbated by social care limitations, as seen in Section 4.4.2.

Social isolation appeared to influence rehabilitation. Claire did not rehabilitate well on the ward but responded very well once in a residential home. She had previously been living at

home, but the family and the patient did not feel it was appropriate to go home so heavily reliant on the Sara Stedy. Claire's niece talked about the environment at the residential home that Claire was discharged to:

> *in that kind of environment, if it increases her, you know, her quality of life because she's got all these little social occasions going on, she's got people to talk to, she's got wide-open spaces to walk to.*

Claire's niece was pleased with how the care home was supporting socialisation and rehabilitation, as well as the care she was receiving:

> *Her care couldn't be better, she does something all day every day, she has two hourly checks in the night, it's brilliant.*

However, Ivy rehabilitated better in the ward environment. Ivy's occupational therapist was questioning whether she was performing so well whilst in the hospital care because…

> *she's getting the care in hospital, that she is getting regular meals, regular medication, she's getting into bed at night you know, sleeping with her legs on the bed, you know, so the care that she is receiving perhaps leads to her to become the best that she can be, and then it's when she's at home that things are obviously breaking down.*

The care at home was not to the level of the care in hospital and Ivy was not having her needs met, which led to her health deteriorating and her returning to hospital. Ivy's daughter noticed the difference in her mother's demeanour when she was in the community hospital compared to how she was at home. She related this to the increased level of care in the hospital compared to at home:

> *So how I feel about my mum coming out of hospital now is I feel really angry actually because, you know, when I was going in to visit her she looked as bright as a button because she was getting round-the-clock care, she had people around her all the time which keeps her buzzing as it were.*

Ivy then added,

> *I was getting so many cups of tea as well weren't I?*

Ivy and her daughter went on to talk about how Ivy was not drinking enough at home and getting urinary tract infections. However, she was avoiding drinking due to the difficulty she had getting to and from her commode safely, so she avoided drinking. Furthermore, she was

alone when she was doing these transfers and at high risk of falling. Social isolation also seemed to come into play with Ivy's daughter saying,

> *and that was why she was so bright because she had someone that she could chat to.*

Ivy enjoyed the social aspect of the day room. In the community she had been unable to access a befriending service because there is no one available and she is not up early enough to attend Age UK, whose buses like to collect by 10 am.

After the second discharge she had a series of falls and waited six hours on the floor for an ambulance, which culminated in a loss of mobility again and an admission to an acute hospital. After the acute hospital admission, Ivy was less mobile than ever as she did not receive much physiotherapy input. Ivy rehabilitated better in the community hospital and Claire rehabilitated better in a care home. In both instances the ability to socialise with peers seemed to be important. Ivy's daughter felt the reason her mother did better in the hospital than at home is because…

> *you lose the enthusiasm because you haven't got that doctor, that nurse, that, you know, whatever coming round in helping you, she's lost her confidence tremendously lost her confidence, and that's not good for her because to be here on her own she needs to be confident that she is not going to fall, that she is not going to lose her balance, that she can get up and walk, and without that confidence she can't do it.*

After discharge, Ivy's daughter felt rehabilitation should start sooner and should be daily to increase confidence, gain muscle strength and prevent cellulitis:

> *If someone came out and said 'Right, this is what we're going to do, backwards, forwards, backwards, forwards', every day was coming in and doing the same thing, eventually that would build her confidence up, certainly the strength up in her legs and if there was continuous movement the cellulitis wouldn't setup, the swelling would stay down and it's, it's a vicious circle.*

Iris provides a challenge to the 'home is best' narrative, whilst Ivy challenges the notion that rehabilitation at home is as effective as on the ward for all people. In both cases a lack of social network was an influencing factor.

Hazel's perspective of why she could not go home and had to be discharged to a care home when she actually wanted to return home was:

> *I can't go home, I've got nobody there.*

If a family member lived at her home she may have been allowed to go home; however, the risks were deemed too great and she was given no choice. Hazel provides an example of how the drive to discharge created a power dynamic whereby the drive to discharge intersects with limited resources and removes patient choice. It also illustrated how the drive to discharge creates a stressor for the family member, who was in his nineties and had to choose a care home within a time limit.

Hospital staff were not unaware that the drive to discharge dehumanised Hazel, leaving her with no choice or control. Hazel's ward nurse reflected on the difficulty of coming into hospital from home and then being discharged to a care home:

> *It's very difficult for these frail elderly patients that we have that come out of their own homes into hospital and then all of a sudden they're not going back and I always feel quite strongly that they don't get the opportunity to say goodbye to their homes, to see the things in their homes ever again and that always kind of hits me really, I think that's really harsh, it's really harsh.*

Hazel's ward nurse showed great compassion when talking about the difficulty of being discharged to a care home and suggested that these patients should have the…

> *opportunity to go home for that one more time, even if it's just an afternoon or a couple of hours, that's the thing that always I think is really sad.*

When talking about the discharge from the perspective of a subjective score, Hazel's ward nurse felt there was a difference between a process score, which she gave an 8/10, compared to a more emotional score. She felt the emotional score was lower due to the 'sudden', 'harsh' discharge to a care home. She said of being discharged to a nursing home when the patient had been living at home until admission:

> *I think sometimes, especially with discharges to nursing homes, is all very last minute, yeah, so I think, you know, although [Hazel] knew that was the plan, you know, all of a sudden the date is sprung upon them and I think that's harsh as well. I mean I know we have to have the throughput but I think it could be, sometimes the planning could be better and the patients could be kept more informed of where we are in the process.*

Hazel's ward nurse is demonstrating a huge amount of empathy and compassion for a patient who will never be able to see their home again. It also shows that nursing staff are not entirely comfortable with the pervasive drive to discharge at the expense of a patient's humanity. When talking about Claire's discharge to a care home having been admitted from her home, Claire's ward nurse commented,

> *It's quite brutal isn't it?*

On the day of Hazel's discharge her brother-in-law reported,

> *The nurses told you that your breakfast would be your last meal you would have there because you're coming here, that as it happens the ambulance was late until the afternoon so you had lunch there.*

In an overlap with resource limitations there was a delay in the transport arriving, which was not communicated to Hazel. The drive to discharge was influencing the staff focus on discharge when the process takes over and the patient's control of the situation is removed. The drive to discharge had an impact on the communication between hospital staff and patients and their families. The consultant community geriatrician described what ideal communication between hospital staff and patients regarding discharge would look like:

> *In the ideal world patient and team would be working towards a discharge date that they all know, and that they're all planning towards, in which the patient felt involved in that conversation. And they would then be, you know … Their relatives and they would be ready to go when the day came.*

However, she also said that,

> *They're [patients] not included in the conversation particularly well. The number of times I go to see a patient and say, 'oh, you know, your discharge is tomorrow.' 'Is it?' You know, and we've made conversations, we've made decisions about people in which we haven't told them this fact, … Yet, I just, I know we could do it better.*

Hazel did not want to go to a care home. She described going home instead of being in the care home as 'heaven'. When asked why it would be heaven, she responded that she liked to 'Sit by my television' and that she didn't mind 'being on me own and I because I see [brother-in-law] most days', which was all the social interaction she wanted. When asked to express what it was that made that social interaction so special Hazel talked about the lovely meals her brother-in-law cooked. She also talked about memories of meals at the golf club

they used to enjoy, which illustrates the importance of shared memories. Also important were 'special programmes' on the television.

Pets were also special to participants and influenced their decision making. Ivy and Jane had cats, and Amy and Zoe had dogs. All four participants were keen to be discharged home to their pets and it was a reason to refuse to go to a care home. Amy wanted to return home…

> *because of my dog, because I don't want her to go down in kennels, she's not a kennel dog, she'd die.*

For the dog's sake, Amy felt she needed to return home. During her interview Zoe was talking about why she did not like hospital. She said there was nothing to do to keep herself busy but mostly…

> *Missed my little dog.*

When discussing her daily activities at home, it was clear her little dog was her main hobby. The hospital occupational therapist also reported that Zoe would not go to a care home because…

> *she is absolutely adamant that she wanted to go home to her dog.*

Eventually Zoe's family friend returned the dog to the rescue centre it had come from as Zoe could no longer care for it:

> *I didn't do that till the last minute because she refused to part with it.*

Caring for Jane's cat was one of the tasks that fell to her neighbour that gradually added to her carer burden, which is discussed further in Category 4: 'Carer burden'.

4.6.2: Decisions and capacity

Within health and social care, choices are reliant on the concept of capacity. The *Mental Capacity Act* (DoH, 2005) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment and is decision specific. Therefore, if hospital staff deem a patient to have capacity they will follow the patient's wishes. However, in the case of Alastair his daughter felt strongly that, returning home again, given previous failed discharges, sepsis, accidental overdose and the state of flat, was a bad decision. She felt that hospital staff did not listen to her and that their focus was to achieve a discharge home regardless of her concerns. Alastair's consultant nurse commented on how during previous admissions hospital staff…

did seem quite adamant that he was okay cognitively or had sufficient understanding of the risks to decide to go home, vascular dementia does have, one of the issues is that people become less aware of their own safety … It's specifically related to vascular dementia more than other dementias.

Alastair's daughter vociferously refuted her father's ability to care for himself at home in between care calls, as evidenced by the state of the flat, two episodes of sepsis, accidental staggered overdose, over-reliance on his neighbour, inability to put away or eat the food delivered and not being supported adequately by social care carers:

Then he went back home the same thing happened again, he was assessed by [xxx] and I said to the lady, because my dad got vascular dementia as well and I said, you know, there're certain decisions perhaps sometimes aren't the best decision for you because you want to be independent but she said he needs to ask for help to receive help.

However, Alastair was unable to ask for help as he was unaware of his deteriorating and health.

Whilst visiting Alastair in hospital, his nursing home manager talked about whether patients had capacity and could provide consent. She then described a version of the mini mental test, which is not an assessment of capacity:

When you talk to them you know, like how long have you been in here, what's the day, who's the Prime Minister, little questions like that you just sort of throw in.

This suggested that decisions are being made about someone's future based on inaccurate information and a misunderstanding of what capacity is. Although it is well known that patients become disorientated to time in hospital, the nursing home manager was making decisions about capacity when they did not know how to assess it or what it means:

You could be talking to a patient and then they just go off at a tangent and you try and bring them back to that conversation and then I have to go and speak to a nurse or someone on the ward to say 'Is this right?'

A more positive and empowering aspect of Alastair's admissions process was the nursing home discussing end of life choices with the patient and the family. Advance care planning helps to ensure end of life care is smooth and that the patient's wishes are respected.

Zoe's case has been discussed at length above but also pertains to the issue of capacity. There was tension between hospital and community views on how Zoe lived with a lot of dog mess and hoarding. Zoe's hospital occupational therapist described the process of discussing the discharge to home with a family friend who was helping Zoe and her sister. The family friend…

> *was very concerned about Zoe going home. So I had to explain, you know, that actually Zoe has got capacity and she wants to go home we just need to try and do what we can to get her home safely. So she agreed to support, you know, getting the room cleared as much as she could which she did.*

However, the concern of the family friend may have been due to her awareness that Zoe and her sister were going to rely heavily on her for the discharge to be successful. The impact of the patient's choice on their informal carer is discussed in Section 4.7.3: Patient choice and the effect on the carer.

4.6.3: Decision making and family influence

Claire's case uncovered issues concerned with decision making regarding moving into a care home and how this decision may be influenced by family members, making it unclear if it was Claire's choice. When interviewing Claire, her niece and the health professionals involved in her discharge, it was unclear if Claire had decided to go into a care home with or without pressure from family:

> *My nephew and his wife, they looked at all the homes around to see what would be beneficial for me, and this one stood out. So it was unanimous, really that they felt I'd be happier here, because I can do what I like to do, if I want to stay in my room, I can, if I want to join in, I can, there's no restrictions.*

Claire's ward occupational therapist felt she could go home with equipment and a care package, as well as intermediate care team input for rehabilitation. Whilst in the community hospital, Claire had not regained any mobility and was reliant on the Sara Stedy. However, her occupational therapist reported that…

> *She was worried about going home, but she wanted to go home … I arranged the access visit with her niece, and when I got there, her niece said to me, oh well she can't possibly come home, she'll have to go into a care home, and I was there for nearly an hour listening to the niece expressing her concerns about her going home, and saying that it wasn't right.*

The occupational therapist went back to the hospital and said to Claire,

> *Your niece tells me that, you know, you want to go into a care home now, and she said, 'well yeah,' she said, 'I think that would probably be the best.' She seemed undecided, I have to say.'*

When asked whose decision she felt it was, the occupational therapist said,

> *I felt it was more her niece's decision and her niece was very, I felt, a very strong character, and, and was, probably very influential in Claire's making her decision … She was probably a bit frightened about the future and what, what's going to happen to me.*

However, Claire's niece's perspective included Claire's experience whilst in the acute hospital and how that may have influenced Claire's behaviour, rehabilitation and decision making.

> *There was so much trauma she hadn't, she couldn't get her head around it, she just couldn't process any of it and she was like, 'Well I can't do it, I can't move my, I can't do anything.'*

Claire's niece stated that she was preparing for Claire to return home and was thinking about creating a wet room, room layouts and so on, when Claire said to her,

> *I don't want to go home , and not only do I not want to go home, I don't want to see it … so that made me feel terrible.*

It is unclear if this decision was influenced by her niece's view of having carers, which she felt was unacceptable and removed patient choice:

> *She's so fiercely independent, she doesn't want people in and out of her house all day and night, but you have no choice do you?*

Talking about the emotions involved and the loss of dignity of carers coming into the home she said,

> *I don't think they [agency carers] get it, don't think they understand. The feelings that are involved in that. I mean hospitals especially because they see so many people, it's like, 'Oh just another one, just another one.'*

Claire's niece perceived that formal care in the home led to a depersonalisation of patients. Therefore, Claire's niece found a care home that she felt was acceptable and Claire was

admitted there straight from the hospital. I spoke to Claire about whether she would like to go home and if her care home placement was permanent:

> ***Claire:*** *I don't know whether I'd be able to go home, I don't know.*
>
> ***Me:*** *Do you think you'll be staying here?*
>
> ***Claire:*** *Not long term.*
>
> ***Me:*** *You wouldn't want to stay here?*
>
> ***Claire:*** *On no, no, not forever … I might go home with carers or something like that, yeah, that's the best option really.*

Claire seemed to think that going home was the best option. However, the care home manager and ward nurse both thought the placement was permanent. But she was also concerned about how family felt:

> *It gives them peace of mind to know that I'm here and looked after, whereas if I wasn't in a care home they would still worry, in my own home, with carers, they would still worry.*

Claire's ward nurse seemed to think that Claire had not been told her placement was permanent and that family were waiting for her to get used to living there:

> *I thought it was a permanent placement, but I can understand sometimes family do say, they have to do it gradually with some patients to ease the burden, ease the blow I suppose, to give them time to adjust to the fact that they're not going to be going back to their own home.*

If this were the case, it is an example of family decisions removing patient choice and control. On balance, the family decision seemed to be based on the quality of the care and carers, which is an overlap with community resource limitations (Section 4.4.2). Claire's ward nurse commented that,

> *I think depending on where, what home you're thinking about, what activities and again, staff can make all the difference in the world, so care's only as good as the staff that are working on the day really aren't they?*

Claire's niece talked about finding the perfect home for her 'precious' aunt and dictated the terms of the discharge home. Andrew's daughter also took matters into her own hands in order to ensure the best care possible. When the hospital was unable to resolve issues with

her father's collar, Andrew's daughter took him to a private clinic, which resolved the issue. She also had previous knowledge of how slow patient transport was and opted for transporting her father home herself. Both Claire's niece and Andrew's daughter shared characteristics of being outspoken, confident and knowledgeable about the health system.

4.6.4: Funding and finances

The data showed that decision making and choices could also be influenced by concerns about finances. Concerns about finances are emotive and stressful and involved the informal carer. Hazel's brother-in-law, who was in his nineties, was given the task of finding a care home for Hazel to be discharged to, in a short space of time. Hazel had lived at home until the hospital admission, therefore this was a weighty decision. When discussing the choice he had had to make, he said regarding cost,

> *Well, [xxx] was 1200, [xxx] was 1100, this was 780. It speaks volumes.*

Hazel's brother-in-law's decision making was based on cost rather than quality of care or the ability to care for Hazel and her fragile pressure areas.

Zoe's consultant nurse referred to care navigator to make sure benefits were being received because finances were mentioned a few times by Zoe and her sister. In the end, Zoe's sister cut care calls down to one a day, which increased the risk of failed discharge and poor health outcomes. Finances also influenced Zoe's choice to go home rather than to a care home. Zoe refused care home as she did not want to sell family home. Zoe said that she was…

> *Always coming home.*

Her sister added,

> *We don't want to sell our house.*

Zoe and her sister did not use a bank, and their family friend reported they had money 'stashed' around the house but they had forgotten where it was amongst the hoarding.

Amy's daughter talked about the cutting of care calls for financial reasons once the period of free care finishes post-discharge:

> *I really would have thought she needed a lunchtime visit as well, but then again, it's all more expense. Because it's all very well, she's got to pay for that, she has to pay, obviously she's got a house like this, she needs to, she pays the gardener, she has a cleaner once a week, it's all extra cost.*

Cutting the care call created a further burden for Amy's daughter as she then visited daily to provide lunch for her mother.

4.6.5: Recuperative care

The loss of recuperative care was raised by participants as an issue as it had been a tool for patients and therapists. Rehabilitation could take place in a safe environment, whilst patients had the chance to try living in a care home for up to six weeks to see if it would be a better place to live than at home as their mobility and independence decreased. The therapies lead said,

> *We have found patients that have been really anti going into a home, want to go into their own home, have gone into [recuperative care at a care home] and have actually found, 'Do you know what, this is really good', you know, the fear of falling and being on the floor … They have been able to make the decision.*

The therapies lead added that recuperative care aided decision making as it allowed the time to make an informed decision:

> *by having a kind of halfway house, where you could have two or three weeks as a trial, what we have found in the past is those that have been absolutely adamant about going home have suddenly gone, 'Well, actually, it's not so bad being in a place like [this].'*

The therapies lead felt the reintroduction of recuperative care would be beneficial for those that have had a large health event and were fearful they could not cope at home after discharge from hospital, but gave them the chance to have further rehabilitation and enablement before making the decision. It also provided the opportunity to find out what aids, adaptations and care might be needed after a change in function. Ivy was an example of someone who may have benefited from recuperative care for two reasons: for more rehabilitation and to try out life in a care home. After three hospital admissions in the space of a few months, regular falls and waiting up to 6 hours for an ambulance to pick her up, Ivy was adamant she did not want to live in a care home. Meanwhile, Ivy's daughter and health professionals were keen for Ivy to go to a care home so that she could sleep laying down in the bed rather than in a riser recliner, which would help her the recurrent cellulitis, to encourage more mobilising rather than waiting for care calls, and to supervise mobility and therefore reduce the risk of falls. Ivy's hospital occupational therapist said,

I think thinking about giving up her bungalow and her independence and her relationship with her boyfriend was weighing on her mind … She still wanted to be able to keep her own place so that they would have time together.

A perceived lack of privacy in the care home setting was influencing Ivy's choice.

Ivy herself said,

I mean this is so nice. My boyfriend painted every bit of this place for me … I've only just moved down here, you know. I don't really want to go somewhere else … I got me birds out there that come and, you know, feed out there, I've got a bird bath that I wanted … You know, and it's lovely. I've got friends from London that come down and meet and see me.

During the second interview, and after Ivy's third admission she was still adamant that she did not want to go into a care home. At the end of the interview her GP arrived and talked to Ivy about the frequent falls and frequent hospital admissions, and how moving into a care home was a matter of 'when, not if'.

This conversation was not recorded but field notes were made at the time. After the GP left, Ivy was very upset, and when her daughter left the room, she told me the main reason she did not want to go into a care home was because her daughter's mother-in-law was being cared for at her daughter's house. She was disgruntled that the mother-in-law was getting this sort of care from family, but she was the one who would have to go to the care home. It was regarding this matter that the consultant geriatrician said,

Well, therein lies a whole host of humanness isn't it … how often do we have enough time to actually get to the bottom of an issue?

Again, recuperative care may have given the time needed to help explore and resolve these issues. As discussed above, there is a reduction in the rehabilitation window due to the drive to discharge, which is reducing the amount of time health professionals can spend helping patients and family resolve these sorts of issues. At this point I had spent at least two hours with Zoe and her daughter and had the chance to build rapport. This is difficult to do for health professionals who have limited time and have tasks to achieve. If someone could have helped the family address this issue, perhaps Ivy and her family could have found a way of helping her to be safer and happy with her home environment, wherever that was. The option of recuperative care would create time and space that is lacking in the community

and hospital. Furthermore, recuperative care would be removed to a degree from the drive to discharge.

4.6.6: Summary

- Choices made are based on many different factors that the drive to discharge may not allow for or anticipate.
- People will not always behave how policy anticipates; for example, rehabilitating better in a ward environment than at home.
- People may not have the social network or confidence that policy expects, therefore, home is not always best.
- The drive to discharge can take away a patient or carer's choice and control.

4.7: Category 4: 'Carer burden'

Informal 'Carer burden' was identified as a category in this study and was associated with the burden created by the drive to discharge and compounded by resource limitations, miscommunication, and lack of resources and support. The informal carer was often 'intrinsic' to discharge, which naturally implies a certain level of burden. Fundamentally the informal carers enabled discharge but also enabled the patient to remain at home after the discharge.

4.7.1: Informal carer demographic and role in the discharge

Participant	Informal carer	Age range	M/F	Role in discharge	Employment status	Other dependants
Hazel	Brother-in-law	90–100	M	Visiting in hospital. Find nursing or care home. Deal with now vacant house and possessions. Next of kin.	Retired	
Amy	Daughter	50–60	F	Visiting in hospital. Waiting at house to let equipment in, organise key safe, coordinate health and social care, take to appointments. Care of dog. Next of kin.	Signed off sick/with depression	Husband, terminally ill
Alastair	Daughter	30–40	F	Visiting in hospital. Does not live nearby. Online shopping. Travel to hospital to advocate regarding inability to return home. Find nursing home. Next of kin.	Compassion-ate leave	
Zoe	Friend (and sister)	60–70 80–90	F F	Take sister to visit in hospital. Clear clutter for hospital equipment arrival. Try to find hidden money. Returned dog to rescue. Advocating for discharge of sisters to same place. Funeral arrangements. Locate family.	Retired	Husband post stroke and Zoe's sister.
Mae	Nil	–	–	–	–	–

Participant	Informal carer	Age range	M/F	Role in discharge	Employment status	Other dependants
Ivy	Daughter	60–70	F	Visiting in hospital. Wait at house to let ambulance crew in. Coordinate health and social care. Answering lifeline calls. Take to appointments. Cleaning, cooking, shopping, feeding cat. Assisting transfers and mobility. Next of kin.	Unemployed	Mother-in-law, older/frail and living in same house.
Jane	Neigh-bour	60–70	F	Visiting in hospital. Answering lifeline calls, cooking, cleaning, feeding cat, medication, manual handling. Only social input for patient.	Self-employed	Own family
Claire	Niece	50–60	F	Visiting in hospital. Liaising with hospital re discharge to home or care home. Finding care home. Organising and taking to appointments. Next of kin.	Employed	Mother, husband with Parkinson's, son with congenital condition.
Andrew	Daughter (and wife)	50–60 80–90	F F	Visiting in hospital. Liaising with hospital re collar care and use. Taking to private appointments re collar. Drove patient home at discharge. Doing all personal care and encouraging mobilisation. Next of kin.	Self-employed but taking a break	Mother. Moved in with parents.

Participant	Informal carer	Age range	M/F	Role in discharge	Employment status	Other dependants
Iris	Son	60–70	M	Hospital visits. Coordinating health and social care. Basic meal prep and cleaning. Monitoring mobilisation to guard against falls. Next of kin. Supported by sister who can drive.	Long-term sick	

Table 6: Informal carer demographic and role in the discharge

4.7.2: Drive to discharge and the effect on the carer

The first subcategory in 'Carer burden' is related to the effect the drive to discharge has on the carer. One of the reasons informal carers are intrinsic to the discharge is because they have to find a care home or nursing home for their family member to be discharged to when the patient has previously been living at home. This is a weighty responsibility as the informal carer is choosing where the patient is going to be living from now on, and are facilitating the transition to permanent care and loss of independence. Claire's niece described the responsibility of finding a good care home when her aunt's 'life in [is in] my hands' and that she was 'completely helpless'. Claire's niece talked about the responsibility of choosing the right care home and putting 'her in an environment that she's going to thrive and not go downhill.' And that 'she could be there for the rest of her life, I'm not going to get that wrong'. Claire's niece was being thorough and reading the Care Quality Commission reports for each care home as well as visiting them and had to explain this to ward staff:

> *You know this is not a five-minute job, I need to know and I need to read those reports, and because I work in one, you're not fobbing me off with going there because she's not, you're just not doing it, it's not going to happen.*

Claire's niece talked about the pressure felt created by the drive to discharge:

> *I was feeling pressured, not bullied … but I felt pressured. I was like no, no you're not, it's not going to happen, and I am really nice about it but, 'I'm sorry, no you're not going to get away with this one.'*

The language used when describing the hospital 'fobbing off' and 'getting away' with pushing for a discharge to any home shows her perception of the hospital priority being discharge, whereas the priority for Claire's niece is the patient's welfare and long-term wellbeing. This use of language also suggests a lack of trust in the hospital's motivations as well as a sense of battling the system to get the right result for her aunt. Hazel's brother-in-law was responsible for finding a care home for Hazel and opted for the cheapest care home rather than a nursing home that could manage Hazel's pressure areas. With a lack of support from family or services he made the best decision he could under pressure and thought he was doing the right thing to protect Hazel's savings.

If family members resist the drive to discharge as Claire's niece did it can appear to ward staff that the family are being awkward or obstructive. The therapies lead described how it appears to ward staff when family push back against the drive to discharge:

> *I would probably say that 75%, if you like, are pretty good and will go out of their way to do what they need to do. You do get some that are not so good, I mean we've got a family at the moment that are digging their heels in because their family member has got to go to a home and they've only been given one home to look at and although they like it, they don't want her to be discharged unless they've got something to compare it to.*

The therapies lead went on to describe the hospital perspective that the patient does not need to be in hospital anymore and how, as a carer of older family members herself, she could understand the desire to compare a few different homes. However, she said,

> *that's not the understanding of it's a hospital bed and it's needed for the next person.*

The data also showed that the burden fell predominantly to women, with only one male family member taking all the responsibility. Amy's daughter, Ivy's daughter and Claire's niece all described other (male) family members living nearby or having power of attorney. All commented on how unhelpful other family members were during the discharge and with caring responsibilities after discharge. Amy's hospital occupational therapist commented that Amy's daughter had…

> *mentioned that she had a brother but she said everything tends to fall to her as the daughter, which she said that's probably quite common and we do see that quite often.*

Ivy's daughter commented on family members saying,

> *the other two are just a waste of space … they live two minutes from my house and they've been a complete waste of space.*

Ivy's daughter clearly felt unsupported by family members that also live nearby. Claire's niece also described her family support:

> *We've got a massive family but you always find that people just don't want to know do they? They just don't want to bother.*

The exception was Hazel's 91-year-old brother-in-law, who was her only living relative, and Iris, whose son lived in her house. However, he was supported by Iris' daughter, who worked full time but did all the driving and shopping and was generally the driving force in the family dynamic. Iris's hospital occupational therapist knew the family well and said,

> *A lot of the decisions have to go by her so although the son lives there I think she's the main decision-maker in the family…So maybe he's not as proactive in things that need to be done, practical things that need to be done…but I think she has family commitments though.*

Two women became the main informal carer, even though they were not family members. Zoe's sister's friend became a carer to them both, and Jane's neighbour became her informal carer. In both cases the caring responsibilities started light and developed into a much greater responsibility. Zoe's family friend started by taking Zoe's sister to visit her in hospital, then at the time of the discharge was the only person fit enough that the sisters knew who could help to clear space for the hospital equipment to arrive. As the sisters became more unwell and were both admitted to hospital, the family friend ended up being solely responsible for organising the hospital discharge and then their funerals. She also tried to help them locate their lost money.

Jane had no relatives, so her neighbour had been helping with day-to-day tasks such as feeding the cat and fetching some shopping, which increased to taking care of bills, managing medication and taking Jane to all appointments. However, she ended up being intrinsic to the success of the discharge and to Jane remaining at home. There was an assumption that Jane's neighbour would naturally take on the responsibility. Jane's hospital nurse said,

> *Planning was started to get her home to her own home which was her choice, with a package of care, and the support of her neighbour.*

Jane had four care calls a day, but she was pressing her lifeline all day and night to summon the neighbour for help. Jane's community frailty nurse said that Jane was pressing the lifeline,…

> *ringing every hour, [Jane's neighbour was] not getting any sleep at night.*

Jane was discharged from hospital unable to transfer out of bed or change position in bed. This meant that Jane's neighbour took on manual handling, as well as encouraging eating and drinking, feeding the cat, cleaning and coordinating services. All the while Jane refused to try a nursing home as her choice was to remain at home. Her community frailty nurse said that she was…

> *waiting to nearer the time when [the neighbour] was moving away, because she knew she had [the neighbour] up until that point.*

When her neighbour moved away, Jane moved to a nursing home and died three days later. Jane's neighbour was stressed by the level of responsibility and said,

> *Nobody's listening to me, I can't get the help that she needs from anybody.*

Jane's choice to go home rather than to a nursing home when she was nearing the end of life was honoured, but at the expense of her neighbour who did not seem to know the gravity of the situation as she was expecting Jane to be mobile and a little more independent.

> *She hasn't been up yet, since she's come home she hasn't been out of bed.*

Drive to discharge places a large amount of responsibility on the informal carer to enable the discharge. The patient's choices also impact on the carer.

4.7.3: Patient choice and the effect on the carer

The second subcategory under 'Carer burden' relates to the effect of patient choice on the carer. Hospital models of care emphasised patient choice and patient-centeredness. Whilst patient choice is important, it is also important for older people living with frailty to have a comprehensive network for them to remain in their own home. Procter et al (2001) highlighted three key issues in their research on the carer/patient dyad when going home from hospital. These were: the complexity of the patient/carer relationship; the assumption that the carer could cope led to other sources of support of the patient not being explored; and the carer's needs were not recognised. They also found that the patient perspective dominated professional understanding of care needs, where the carer has been defined by

the patient or professionals, who is then obligated to conform to the expectations (Procter et al, 2001). This felt particularly true for Jane's neighbour, who had been supporting Jane emotionally and physically for some time as her health declined. However, Jane's final admission to hospital was a 'step up' placement to manage medication and pain as she reached the end of life. She was discharged unable to transfer out of bed and had become significantly more dependant. There was an assumption that Jane's choice to go home rather than to a nursing home would be supported by her neighbour. However, her neighbour had not realised she would be called hourly by Jane day and night and would be assisting with manual handling as well as all household tasks. The general practitioner described the difficulty of describing to carers what their burden may be like:

> *I think it's also tricky to make people explicitly aware because I don't think even we know what they're going to be required to do. And I think part of that is because you don't know how someone's going to manage when they go home … and you also can't predict how carers are going to respond.*

In an overlap with resource limitations, the general practitioner also described how a lack of occupational therapy assessments is a missed opportunity to get a clear picture of the patient/carer dyad:

> *That's also a really interesting dynamic and you probably see more how that's going to actually, what that's going to look like [after discharge] if you go to do a visit … you need to see that dynamic in action and the only way you're really going to see it is when you watch them interact at home a little bit. And I think it's a really artificial environment on the ward.*

However, the drive to discharge and resource limitations is reducing the opportunities to observe these interactions and therefore decreasing the ability for health professionals to provide support to the carer.

The data showed that the dyad can be a triad or more. Zoe's family friend was caring for her own husband, who had had a stroke, as well as for Zoe's sister. Amy's daughter was also caring for her terminally ill husband. Ivy's daughter was also caring for her mother-in-law, who was also living with much frailty and was blind. Claire's niece was also caring for her mother, who was living with frailty, her husband with Parkinson's and her adult son with a congenital condition. Andrew's daughter had moved in with her parents to support them both whilst caring for her father. The therapies lead commented,

What we're finding as well, because our patients are older, those carers not only might have two older, frail people to look after, but they're actually older themselves.

In this study it was a little more complicated than that, as in the case of Andrew who was being cared for by his wife, who in turn was being supported heavily by their daughter; also, the case of Zoe, who was discharged to the care of her sister, who became increasingly unwell and both sisters became dependent on the support of their family friend. Zoe's community occupational therapist felt that Zoe's sister was caring out of duty:

They haven't got a great relationship, the property was their parents so they're kind of living together by default and they haven't got a great relationship. So I don't know whether Zoe's sister is caring for her out of, for her out of duty rather than out of because she wants to.

Zoe's family friend and Jane's neighbour both reported feeling stressed and unsupported. Ivy's daughter was also worried, stressed and frustrated by her caring responsibilities and her mother's choice to remain at home, rather than go to a care home where she would be better supervised regarding falls and would not spend up to six hours each time sitting on the floor waiting for an ambulance. She described caring for her mum as…

very, very time consuming. I'll do anything for my mum, she knows that, but I think it's unsafe for her, so I'm worried now, constantly worried because I feel its unsafe for her being here on her own.

Ivy's daughter also described 'running around' after her mother-in-law at home and the daily visits to her mother to supplement the three care calls. As discussed above, Ivy's daughter received little support from other family members and reported 'screaming quietly' into her pillow or crying at night. She also described anger at her mother's quick deteriorations since she was discharged home:

I feel really angry actually because … she looked bright as a button [in hospital] because she was getting round the clock care, she had people around her all the time which keeps her busy as well. And she's got another water infection [at home], purely because she's not drinking enough because it's difficult for her to drink.

When asked about her employment status, Ivy's daughter responded:

> *Fortunately not … I don't work fortunately. There aren't enough hours in the day for me to work, seriously …I have six adults in my house that I cook and clean and wash and iron and literally do everything for.*

Ivy, Jane and Claire's informal carers would all be classified as 'sandwich generation' or even 'senior sandwich generation' (Wassel et al, 2016), whereby they are caring for adult children as well as family or neighbours who are older people.

Amy's daughter described her mother as 'difficult to please' and said, 'I need to be here for every appointment.' Amy found the care 'hit and miss' and would pass her stress on to her daughter, which illustrates a little the state of the patient/carer dyad. She also found that when Amy chose to reduce care call calls from three to two, this caused an increased burden because she then visited daily at lunchtime as well as in the evening, in total two to three hours a day. Meanwhile, her partner was very unwell and nearing the end of life. Amy's daughter found limitations in the social care system frustrating and 'stressful' and she felt she was constantly 'jumping through hoops' to get the care she felt was appropriate for her mother as they were self-funding. Consequently, Amy's daughter had been signed off work sick with 'reactive depression':

> *They ask you do you want to go on anti-depressants, I'm like 'no' because it's not something in my head is it? It's something happening, and giving me tablets isn't going to make it go away.*

Alastair's daughter had been signed off work on compassionate leave. Zoe's family friend said that it was 'serendipitous' that she had recently retired when her caring burden increased. Jane's neighbour was self-employed and trying to keep her business going whilst answering Jane's frequent calls for help. Andrew's daughter was self-employed and had taken time off work to care for her parents. Iris's son was signed off long-term sick:

> *It's good in a way that I no longer work. So obviously I'm home with mum, yeah so something good comes out of something bad I guess.*

However, Iris's daughter also visited every day after work to do the things her brother could not.

4.7.4: 'It's a lot to keep track of!' (coordinating services)

The data showed that burden is also created for informal carers through the need to coordinate services which are fractured, with a lack of communication and patients waiting for services to start. This burden is made worse by a lack of resources such as occupational therapy home assessment. The general practitioner talked about lack of occupational therapy home assessment causing an increased reliance on informal or formal carers to ask for aids, adaptations or services:

> *Unless families are very proactive and ask for it, or the carers ask for it, and actually it feels often they don't even know what they should be asking for because they don't even know it exists.*

The situation was further complicated if the patient had not been part of the social care system before. The consultant nurse described the system post-discharge formal care provision procedure:

> *The system is if people haven't had a care package they go home with [agency] nurses, who are a private company who provide care, and then after three days if they still need care then the enablement team come in and they can stay for up to 6 weeks, and then if they need a care package at the end of that then they will have a social services assessment and be financially assessed and everything and that care will be organised if the person, you know, if it's decided that it's financially their responsibility they may choose not to have a care package, so that is also another issue.*

The data showed a great deal of confusion on the part of the patients and carers regarding who was doing what and when. The system of two different care agencies visiting before settling on the third permanent agency is confusing to patients and carers. Patients who are living with frailty are reliant on their informal carer to keep track of the agencies, the community rehabilitation, community nursing appointments, as well as to provide transport to hospital appointments.

Ivy's daughter described what it is like when her mother tries to conduct her own affairs but loses track:

> ***Ivy's daughter:*** *She's had a physio come and assess her and she should have come this week and that was another person who should have turned up on Wednesday,*

or mum said it was Wednesday but she didn't turn up. So, whether it's Mum's got the date wrong I don't know.

Ivy: *I know she said something about 2nd January but I weren't sure what that was, but she never got in touch with me anyway so I don't know what it was all about now.*

This is just one example of the many incidences where informal carers were trying to decipher what had happened and then intervened to ensure the correct services were provided in order for the patient to remain at home safely. The situation became more confusing after the third discharge because community services had changed. Amy's daughter also reported similar issues when, for example, Amy cancelled the intermediate care team when her daughter was not present for the phone call. This meant that Amy did not receive the physiotherapy she needed to improve her mobility and prevent falls. Furthermore, the hospital was under the assumption that physiotherapy would continue in the community; this is one rationale that supports the drive to discharge.

The coordination of services and lack of support from family was most evident for Ivy's daughter when she went on holiday to Jamaica, where she was answering phone calls from community services and finally from ambulance services and the hospital when Ivy fell again and was admitted to an acute hospital. This meant that Ivy's daughter 'finally relaxed' when her mother was admitted to hospital because she knew she was safe and cared for in a way she was not at home. However, Ivy felt a great deal of guilt at the thought of spoiling the holiday. Unfortunately, this third hospital admission caused further issues as Ivy received no physiotherapy or occupational therapy input and came home less mobile. During the second interview with Ivy and her daughter, conversations about Ivy moving to a care home were becoming more intense.

Keeping track also involved chasing support when it was not forthcoming. This requires an informal carer who knows who to phone and what to ask for, as the general practitioner is quoted as saying above. As seen above, three referrals were made to the 'HUB' regarding Zoe and her needs once in the community, but we have also seen that there was a lack of action on the part of social services, and Age UK refused to visit because of the state of the home environment. In the end it got to the point where Zoe's family friend called the Intermediate care team. Zoe's community occupational therapist said that the team had received phone calls from the family friend, who was a retired nurse, when things were

reaching crisis. Due to the lack of support from social services the family friend took on the burden of finding support for the sisters. She called…

> *saying that 'look, they're really struggling', she had phoned social services twice, was getting nowhere with those, therefore that's why, she was just like 'look can you do something?' So I was like 'right, OK, I'll go out', so we got ready, went out and it was horrendous basically.*

Zoe's family friend could see that the sisters were going into crisis and was also frustrated by the lack of support from the general practitioner.

> *Trouble is the GPs keep changing and they don't know what the person was like before. To me, it was obvious because I knew what they were like before.*

The drive to discharge constantly pushed but provided limited support to the carer who was taking on a large responsibility. Claire's niece and Andrew's daughter were both perceived as strong personalities because they pushed for services or information. During the interview, Claire's niece listed other times she had to 'fight', in addition to her push back against the drive to discharge her aunt to any care home as soon as possible. These other incidents included trying to get the ambulance to come sooner for her aunt who was laying on the floor bleeding, and after discharge to get her aunt's glaucoma issues addressed. She talked about dealing with health services:

> *It's frustrating because nothing is ever straightforward, nobody ever does their job properly, everybody's totally incompetent, everybody loses everything, nobody can fill up one sodding appointment to another … there's a lot of muppets out there … it's very frustrating.*

Andrew's daughter was concerned that her assertiveness when trying to get information on how to deal with collar care came across as 'arsey'. She too talked of a 'fight' and getting cross with the lack of support in how to deal with the collar:

> *I actually went in one day and that was on back to front … I mean I kept asking questions … I mean I did have a couple of harrumphs at times but then tough. Tough, yeah.*

Andrew's daughter appeared to feel a little conflicted about having to be so demanding in the face of limited physiotherapy input on the ward but was 'tough' because she was fighting for her father. Physiotherapy input was limited as this particular community hospital shared

its therapists with the community team and therefore therapists were often pulled off the ward to see patients in the community. There were so few physiotherapists working on the ward that during interviews I could only talk to a physiotherapy assistant.

Andrew's community physiotherapist recognised his daughter's 'frustration' and understood that it was due to lack of support whilst in the hospital:

> *She's had to pull out all the stops and not get the support.*

Andrew's daughter found her own way of dealing with collar care:

> *The hospital put it on back to front so … I can see the frustration and I can see at the end her just going look you, know, we're getting on with it now, just don't, almost like I don't bother anymore, you know, we've had it … we've found our own way of doing it.*

Consequently, Andrew's daughter lost trust and disengaged from health services. Andrew's community physiotherapist commented on the loss of trust:

> *Trust, they've broken the trust and it's usually that and in all my experiences of people that are like that it's usually a son or daughter that is usually like that, the assertive daughter or the assertive son, 2 or 3 visits in you usually start getting a bit of a story.*

There was one participant who had no one fighting for her or coordinating her care.

4.7.5: When there is no informal carer

Mae was the only participant with no informal carer to enable the discharge and to support her to remain in her place of choice. As described above, informal carers are 'intrinsic' in the discharge process, but the data showed that they are important in helping the patient to remain in the place of their choice. Mae had no informal carers and lived in a residential home where only the assistance of one person is provided. If Mae needed the assistance of two people to mobilise, wash and dress she would not be able to stay in the care home of her choice. Mae's community physiotherapist found that the care home was not prompting rehabilitation and as there were no family members, there was no one else to prompt and take up the burden. Mae's community physiotherapist talked of an issue in some care homes such as Mae's where…

> *Normally in care homes they don't because they are very time constrained and I think again, they follow their own care plans which is their own personal care.*

Due in part to resource limitations, but also due to different priorities, the care home was not helping implement physiotherapy care plans to support rehabilitation. This increases the risk of the patient not becoming as mobile as they could. In the case of Mae, the worry for the physiotherapist was that because this particular care home needed their residents to require no more than the assistance of one to mobilise and go to the toilet, Mae would be asked to leave. When talking about how Mae had no children or close relatives and was reliant on the care home to support her rehabilitation, Mae's community physiotherapist said,

> *This is the thing because they thought that that's not their own job and everything depends on the rehab, on us, on community like okay let's slip her back to them and ask them to come and do the exercises again.*

She also mentioned that there is an ageist attitude, where patients are treated like naughty children who will 'show off when the physio is about' and 'will do it for you, but will not do it for me'.

The care home underestimated the patient's ability and focused on social goals and basic physical needs, rather than the bigger picture rehabilitation goal, with a view to being able to continue living in the same place. This is also a mismatch in expectations between community physiotherapist and care home, with the different perspectives of rehabilitation and enablement versus care needs being met. As a counterpoint, as discussed above in Section 4.5.4, Claire's experience is an example of when a care home is fully supportive of the physiotherapy care plan, which results in a good outcome.

4.7.6: Summary

- The drive to discharge, resource limitations, mismatches in expectations and patient choice all cause a burden to the carer, which is exacerbated by a focus on patient-centeredness rather than the patient/carer dyad.
- The carer needs to be taken into account as they are 'intrinsic' to the discharge process and ensuring the patient remains in their place of choice post-discharge.
- The carer is a valuable resource that is not inexhaustible. They are also a future NHS user and the drive to discharge risks becoming a loop that creates more patients.
- Caring for an older person living with frailty is hard work and stressful.

- When there is no informal carer, the patient is reliant on community services and care homes, whose agenda may not match with the patient's.

4.8: Core category: Drive to discharge conveyor belt

The perpetual push to discharge patients was conceptualised as the 'Drive to discharge conveyor belt'. The drive to discharge conveyor belt represented the dynamic process that was experienced by stakeholders in the discharge. The pervasive push to discharge patients as quickly as possible dominated the discharge process and influenced the categories. The general practitioner described the managerial drive to discharge as being an effort to relieve pressure on acute hospital beds:

> *There's a delay in discharging people [from the community hospitals] which means there's a delay in getting people out of the acute trust.*

As a result of the pressure to relieve acute hospital beds, the community hospitals are compelled to create space for those patients who cannot return home. The consultant community geriatrician described what had happened since the Frailty Team had taken over the medical care of the community hospitals:

> *Since we have started the length of stay has significantly gone down in the areas where we've worked … So now we see around 200 more patients in the community hospitals in a year in comparison to previously.*

The emphasis on turnover illustrated the managerial pressure to discharge patients as soon as possible. The general practitioner agreed with the therapists interviewed, that the community hospitals were not providing rehabilitation:

> *Basically, it becomes an intermediate step to going home, I think, more than it becomes, it's not a rehab placement.*

This quote indicated that perhaps the community hospitals are now a 'step-down' to going home and no longer rehabilitation wards, but this message had not been communicated or made explicit to the hospital and community therapists. The therapies lead describes the ideal situation from the perspective of therapists:

> *So we feel that, actually, it's better to keep them in the hospital a bit longer so that we can do a bit more work with them, so that they are not just going home at a standard where they are potentially able to cope, but actually we're sending them*

home nearer to their baseline, just purely because there is a gap in that, between the hospital and community input.

However, the consultant geriatrician referred to the pressure being 'high to reduce the length of stay', but argued that her stance is that this is appropriate:

hospitals aren't good places, but that story hasn't been sold properly, the story is all about, you know, people feel like they're being pushed through it, when in fact, you know, if we solved that … If the story was right it would be, you know, I want to get home because it's going to be better for me.

Described here is the selling of a story or narrative that is the managerial or medical narrative, which is influenced by the drive to discharge. This is at odds with the rehabilitation model of care and may be at odds with the patient narrative as described in the literature review and illustrated by Iris, who did not feel ready to go home and was requesting a few more days of rehabilitation to increase her confidence and independence before the transition. The data suggested that the community hospitals had a new role with a shift toward step-down care that relieved pressures on acute hospital beds with demographic, economic and policy contexts also applying pressure to community hospitals and pulling them in different directions, which was evident in this study. However, this new step-down role has not been communicated to therapists or patients as the push to discharge takes over, which then dictates how community hospitals are run. The pressure to rehabilitate more patients, in a shorter space of time is described by Ivy's ward occupational therapist who remarked that…

The turnover in the community hospitals has increased dramatically, so perhaps these days people don't get as long to rehab and, you know, where they would have once upon a time when I first started working in this environment, there is an onus on getting people in and out.

Ivy's ward occupational therapist added her thoughts on how the discharge conveyor belt was influencing the transition from the hospital to the community:

I think the consultants want them, as soon as they're mobile and able to get to the toilet on their own, then they feel that they should be followed up by ICT and community services so that they're only here [a short time].

Claire's community physiotherapist compared her experience in a different Trust and geographical location to their current Trust:

> *I'm definitely noticing over this four-year period that I've been down here that as soon as a patient is medically fit, they're out, that's it. It doesn't seem to be any communication between the MDT, it doesn't seem to be any kind of respect to the opinion of the physiotherapist, and I've spoken to senior physiotherapists in the acute setting that have said 'whatever we say it's overridden, it doesn't matter, if there medically fit, they're out'. But if the patient can't function at home there just coming straight back into hospital.*

The term 'medically fit' arose regularly as a reason for discharge and illustrated how the medical agenda can outflank the rehabilitation one, such as Mae's ward nurse who described Mae as 'medically fit to be discharged'.

Mae's ward nurse described the role of the community hospital for Mae as…

> *making sure she has reached her potential, and we can't do anything further for her, making sure medically there's nothing that we haven't sort of not touched on.*

However, Mae did not achieve the goals the ward physiotherapist had set and she did not return to her baseline. This revealed different views on what 'potential' was and how 'fit' someone was to return home. When asked to score subjectively out of 10 how the discharge went, Mae's ward physiotherapist rated it 7 or 8 out of 10 as the patient did not achieve the goals set at the beginning of the admission. When asked what would have made Mae's discharge a ten he responded,

> *I think with time she … would have been independent … It [the rehabilitation goal] wasn't necessarily over-ambitious but it was, obviously she, she wanted to be as independent as possible.*

There seemed to be a conflict where the ward physiotherapist said the patient wanted to be independent and that the goal of independence was not overly ambitious, yet this goal was not achieved before discharge. This suggested that a goal other than the patient goal was used to determine when discharge should occur. The rehabilitation plan was overridden in the drive to discharge, where basic safety levels were met. When discussing Mae, 'minimum dependency' and 'safety' were key words used rather than 'reaching potential' or 'premorbid level'. Mae was being discharged to a residential home where she could receive the assistance of one person, so perhaps it was considered more acceptable to discharge

without reaching the therapist or patient goals, rather that she was deemed 'safe' and would have her rehabilitation needs picked up by community therapists or the residential home. When asked why Mae was not kept in a further week to reach her potential before discharge, Mae's ward physiotherapist commented,

> *There was no reason why to keep her on that week when she can have that rehabilitation at home in the end, so with the same outcome.*

The pull that therapists were feeling between their model of rehabilitation and the managerial model caused internal conflict and distrust in the system. The drive to discharge agenda was queried by the therapies lead as not being for the benefit of the patient, but rather for the benefit of the system:

> *We are still, as NHS workers, being told that everything we do, every change that happens is for the good of the patient. I think that is absolutely not true, and I feel that actually, patients are at the bottom of the pile, because of targets we have to hit, CQC input, CCG input, all of these organisations want us to do something and it is not necessarily for the good of the patient, and I don't want to come into this or to work into the NHS to not be patient centred, … definitely I felt over the years that I am not doing the best that I would want to do for a patient, because there seems to be this agenda that we've got to fulfil and it's not necessarily for the good of the patient.*

A lack of trust, owing to the managerial drivers and demands, is evident here. The drive to discharge agenda also created distrust within the community. Hazel's care home manager talked about the process of the patient being transferred from hospital to a care home and how the hospital liked the process to be quick:

> *They want their beds … they like to go pretty quick because I know they're always chomping at the bit to get them discharged and out because they need the beds. So quite often we will get a phone call from the family saying 'oh they've given us seven days, we need to find somewhere, we've got to get them out.'*

It was evident that she felt the drive to discharge was concerning the need to free up beds, rather than in the patient's best interests. The details in this quote show an overlap with Category 4: 'Carer burden', as the drive to discharge rushed the transition and created a burden/stressor for the carer.

The drive to discharge was reducing the time spent discussing difficult topics, which is particularly important when addressing issues around frailty. The reality of living life with increased frailty after an episode of reduced health and function needs to be communicated to enable informed decision making about care. When patients go home below their premorbid level this also has an impact on carer burden. The consultant community geriatrician said,

> *I don't think we are open enough about the fact that what that means if you need to go to the toilet when the carers are not there you will have to go in your pads, and I don't think we talk about that openly enough, and when it becomes a reality to the patient they … It's horrid, imagine somebody said that to you or me.*

The consultant community geriatrician talked about the societal issue of avoiding facing up to failing health as frailty worsens, but that she tried to promote conversations on the topic:

> *People don't really want to envisage what's coming, and I talk about it a lot in when I go and see people at home, you know, and also I talk about hospital admissions, and would you want us to try and avoid it if you could, et cetera et cetera. But people often do they just say, 'well I hope it's not going to be that bad,' but yeah, I'm not sure, that quite how would we have this conversation? I think actually what we have to do is rather than have this conversation, I think we have to make it better.*

However, the consultant community geriatrician acknowledged that communication around these issues needed to improve. As seen in Section 4.5.2: 'Hospital/patient or carer mismatch' the drive to discharge was influencing communication and a lack of involvement with patients and family. It was also influencing multidisciplinary communication. Communication became rushed, not personal, dismissive and uninformative, which resulted in unhappy patients, family and health professionals.

The drive to discharge conveyor belt is at odds with the choice and control rhetoric in policy. Community services are not always available to pick the patient up immediately after discharge. Choice is also limited to the services available, as in the case of Hazel, who wanted to go home as per the 'home is best' rhetoric, but there were not the services available to support someone with her physical limitations and lack of social network. Instead she had to go to a care home that she did not want to be in, which was chosen based on low cost. The drive to discharge caused pressure on resources that are not available; the informal carers are catching their family members as they topple off the conveyor belt and filling the gaps in social care and rehabilitation, thus creating a burden. For example, due to a

complicated family dynamic, Ivy did not want to live in a care home even though remaining at home was becoming dangerous. In this case, a lack of resources intersected with the patient's choices to create a carer burden. In order to respect Ivy's choice, her daughter was pushed to her limits to enable Ivy to remain at home. The drive to discharge ensured that Ivy did not receive enough rehabilitation to be independent before going home and rehabilitation did not commence in the community. The drive to discharge conveyor belt pushed patients into a situation where they may not be supported as soon as they transition into the community. An already complex situation that is an intersection of resource limitations, mismatching expectations, variable communication and choice and control, becomes increasingly complex and creates increased carer burden, with the perpetual push to discharge as soon as possible.

4.9: Summary of chapter

In this study, the substantive theory, which described discharge from hospital to the community for older people living with frailty in the last months of life, was conceptualised as 'Drive to discharge conveyor belt'. The tentative theory integrated the varied perspectives of stakeholders in the discharge process. It acknowledged the complexity of the process and perspectives and how intrinsic the carer is in the process. Matters causing complexity were the drive to discharge, resource limitations, mismatches in expectations, communication issues, and the innate humanness of patients and carers together with the complexity involved in decision making. This chapter has presented the core category and the four dynamic, interrelated conceptual subcategories which form the basis of the emergent theory. Raw data were used to supplement the text of each category, which has been reported separately, thus demonstrating that the findings were grounded in the data. The core category has also been presented in relationship to the four conceptual subcategories and the construction of the emergent theory has been examined. In the next chapter, this emergent theory and its underpinning assumptions will be considered and compared against the existing theories regarding discharge from hospital, care of older people living with frailty and end of life care.

Chapter 5: Discussion

5.1: Introduction

This chapter presents a discussion of the findings. The aim of this study was to explore discharge from hospital of older people living with frailty who are approaching the end of life. The study aimed to include stakeholders involved in the discharge process, including the patient and their informal carer, as well as hospital and community staff, and to develop a substantive theory that accounted for and explained the processes and experiences of discharge from hospital for older people living with frailty who are approaching end of life. Following a constructivist grounded theory approach, the discussion in this chapter is a synthesis of the research findings, the relevant literature and my own interpretive perspectives (Charmaz, 2014). The prior theoretical work is acknowledged and the discussion utilises intersectionality as a conceptual framework to consider and position the new substantive theory in relation to existent theories and demonstrates where the work fits into or extends the existing literature and theories (see Section 3.6.2.1 in Chapter 3 for a description of intersectionality).

The literature paints a picture of a system in flux and under pressure due to demographic, economic and political forces. Into this system enters an older person living with frailty, who brings with them a lifetime of experiences and determinants of their current health. An illustrator helped me to conceptualise the drive to discharge conveyor belt theory in visual form. Full permission has been given to use the illustration in this thesis.

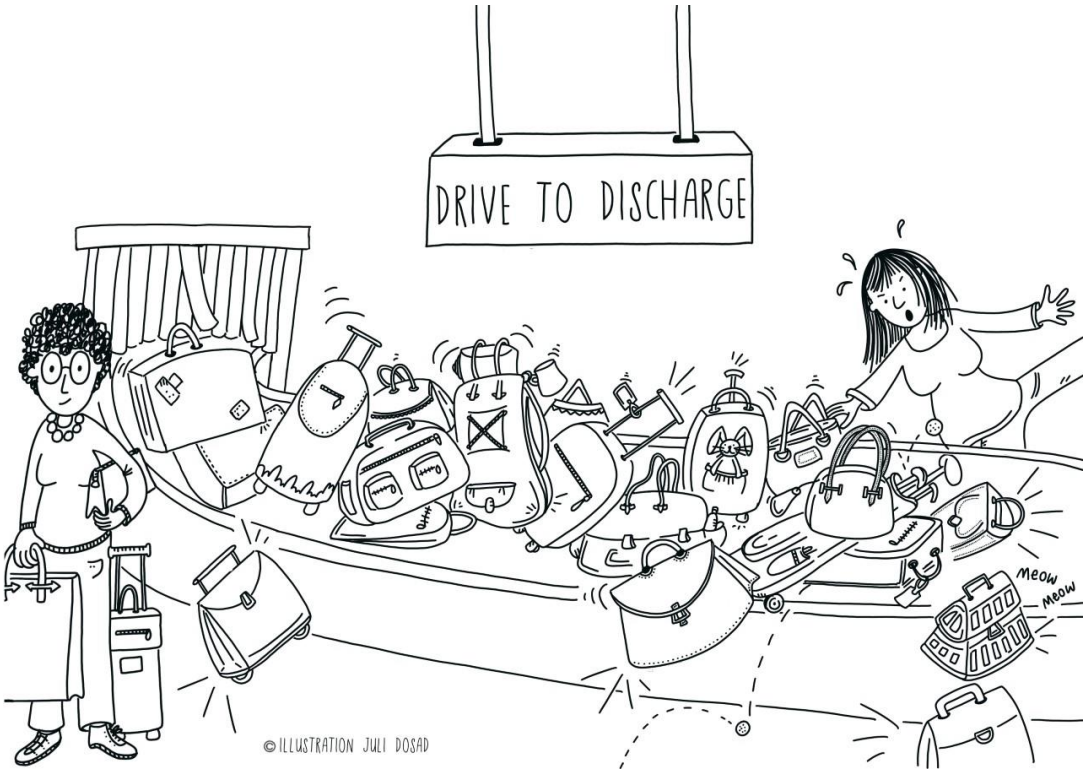


Figure 14: Illustration of the drive to discharge conveyor belt for older people living with frailty who are approaching the end of life

The illustration captures the complexity of the drive to discharge, which is initiated by limited resources and high demand in the acute hospitals, which creates a demand for beds. Acute hospitals want to discharge their patients back to the community, but there are limited resources in the community and patients may not be ready to go home due to further rehabilitation needs or investigations/medication. The pressure is then passed on to community hospitals to provide step-down beds for acute hospital patients. Thus, the need to create bed space continues the drive to discharge through to the community hospitals. The findings showed a situation where patients are being admitted and then discharged quickly. The therapists were most acutely aware as they were unable to provide the rehabilitation they used to, which at one point was a standard six weeks. The drive to discharge pushes patients out into the community, where services such as intermediate care are not picking the patients up and they are waiting several weeks for rehabilitation to continue. This can lead to readmission and the patient going back around on the conveyor belt. The illustration shows the point at which patients are transitioning between hospital and the community and conveys the constant push to discharge regardless of the resource limitations and patient needs. The woman on the left is a community service who is trying to collect all the patients being discharged. The lady at the back is a carer who is having to

exert herself in order to stop her family member falling off the conveyor belt and falling through the health and social care 'cracks' (Borgstrom, 2016a). This is an important element of the illustration as a significant finding of this study was that of the carer, their burden and their intrinsic role in facilitating discharge, filling in gaps in services, coordinating services and enabling the patient to stay at home. The drive to discharge/carer intersection will be discussed further in Section 5.6.3. The different bags capture the heterogeneity of the older people living with frailty juxtaposed with the homogenising drive to discharge.

The constructivist grounded theory methodology and use of situational analysis resulted in an increased understanding of stakeholder perspectives of the discharge from hospital of an older person living with frailty, who is considered to be in the last months of life. The theory presented in this study was based on the analysis and interpretations of the participant interviews. The substantive theory of the 'drive to discharge conveyor belt for older people living with frailty who are approaching the end of life' described the experience of older people and their informal carers, as well as health professionals in the community hospital and community services. The theory thus differs from existing studies as it is contextually situated in the experience of not just older people who are living with frailty, but also the other stakeholders involved in the discharge. As discussed in the literature review, only Hanratty et al (2014) has previously included discharge from hospital at the end of life and multiple stakeholder perspectives. The Hanratty et al (2012) study found that over the years carer experience has changed very little, despite the implementation of policies. The study also recommended the need for identification of patient and carer skills and how to extend them, as they managed many aspects of end of life care themselves. The Hanratty study findings suggested that the patient and carer voice needs to be strengthened, especially in the hospital setting. This is also echoed in the literature regarding discharge from hospital for older people living with frailty at the end of life, which is scant. Education of patients and carers has the potential to benefit the discharge and reduce hospital admissions. The literature and policy highlight the importance of diagnosis to enable access to palliative care and that older people with frailty do not access palliative care as frequently as someone with cancer due to the 'dwindling' nature of frailty, which ties in with the medicalisation of ageing and death discussed further in Section 5.4.2. The literature review critiques the policy around the notion of 'home is best', as well as choice and control together with a lack of service integration, with older people 'falling through the cracks'. Furthermore, coordination of care is required to benefit the patient and discharge (Ellis et al, 2016). The importance of carer involvement both in the discharge and ongoing support after discharge has also been

highlighted in the literature and was a key finding in my study. Figure 13 in Section 4.3 provides a 'participant map' that may be helpful to refer to for this chapter for orientation purposes.

5.2: Intersectionality as a lens

This discussion chapter will use intersectionality to look at the intersecting axes regarding the 'drive to discharge conveyor belt' and the older person and their carer, which in turn will inform the study recommendations. As described in Section 3.6.2, intersectionality will enable the acknowledgment and exploration of the complexities inherent in the intersecting axes for older people and their carers, who are subject to the drive to discharge conveyor belt. Furthermore, an intersectional framework will enable the exploration of social and health inequities and the power in the drive to discharge, as well as in healthcare interactions. Intersectionality will also show how a relational viewpoint may improve patient and carer experience and increase social justice for older people living with frailty and their informal carers. In addition, in keeping with constructivist grounded theory, the intersectionality paradigm encourages researchers to reflect on their own social identities and how their beliefs and preconceived notions shape their research (Collins & Blige, 2016). A Venn diagram will be used as a visual aid to describe and interrogate what happens at the individual intersections and how they come together to produce what is seen in the findings.

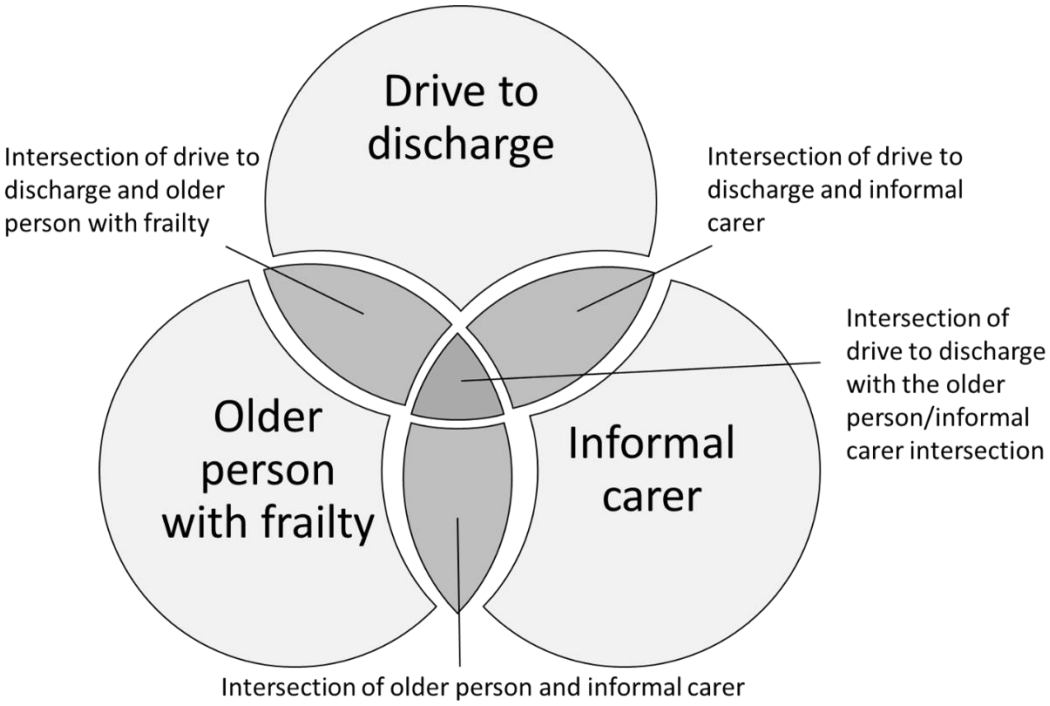


Figure 15: Venn diagram to illustrate intersectional analysis of the drive to discharge

Further to the discussion regarding intersectionality in Section 3.6.2, intersectionality allows for the examination of the drive to discharge conveyor belt, what creates it, what perpetuates it and how it impacts on patients, carers and health professionals. As Greenhalgh and Papoutsi (2018) said of complexity in healthcare,

> *Complex systems have fuzzy boundaries; their interacting agents operate on the basis of internal rules that cannot always be predicted; and they adapt, interact and co-evolve with other systems. Crucially, complexity is a feature of the system(s), not merely a characteristic of interventions.* (p.1089)

Greenhalgh and Papoutsi (2018) call for a paradigm shift in health services research toward the embracing of complexity. However, in this example they are only talking about system complexity, which tends to be prioritised over the human/relationship complexity highlighted in the findings, in addition to system complexity.

Interviewing a variety of stakeholders has meant gathering many different viewpoints and experiences of the drive to discharge. The findings made it clear that not only were older people living with frailty not a homogenous group, nor were their informal carers or health professionals. There was a clear split between hospital and community health professionals' experiences as some were adding to the conveyor belt, whilst others were trying to pick up from the conveyor belt. There were common themes in what participants said, but all experiences were unique. The drive to discharge has the potential to oversimplify people, their needs, relationships and experiences. Corus and Saatciolgu warn that,

> *Any research study that focuses on vulnerable populations, however well-intentioned, risks an essentialist approach, where researcher might assume marginalized groups are homogenous in their experiences.* (2015, p.416)

5.3: The drive to discharge

Collins and Blige (2016) emphasised the importance of viewing intersecting relations in context in order to ground the analysis. It is important to be aware of particular historical, intellectual and political contexts and how they shape what we think and do. This section aims to set the 'drive to discharge' element of Figure 15 (above) in context, before looking at the other two elements and how they intersect.

5.3.1: Context of the drive to discharge

The drive for services to cope with the current challenges, as described in Section 2.4.1, gives rise to the drive to discharge patients as quickly as possible from acute hospitals, which is having an impact on community hospitals. Davidson et al (2019) looked at community hospitals, patient and carer experiences of them and how community hospitals relate to the community in which they are situated. The study interviewed staff, volunteers, community stakeholders, managers and commissioners. The Davidson et al (2019) study provides context to my study as recruitment for my study was from four community hospitals and the findings of my study overlap with theirs. They found that patients and carers valued the closeness to home, the hospital environment and atmosphere, the holistic/personalised care and support during difficult psychological transitions. Patient and carer accounts highlighted the importance of considering the functional and interpersonal, social and psychological dimensions of their experiences. They found that the relational quality of care (rather than transactional) was challenged by patients being drawn from outside the geographical area and by pressure on staff, recruitment challenges and growing pressures on beds. The study drew attention to the fact that community hospitals are under pressure due to demographic, economic and policy contexts, including the withdrawal of GPs and 'shifts toward step-down care' (Davidson et al, 2019, p.vi). As with my study the GPs no longer run the community hospitals and they are now run by a geriatrician from the acute trust, with a focus on relieving pressure on acute hospital beds. Power is shifting to accommodate the needs of the acute trusts. There are nearly 300 community hospitals nationally in the UK, with 97% providing rehabilitation. Gladman et al (2016) argues that rehabilitation lies at the heart of best practice for older people. However, rising emergency admissions and reductions in acute hospital beds (leading to shorter lengths of stay) 'limits the scope for rehabilitation in general hospitals' (p.1). Therefore, patients are being moved to the community hospitals for further rehabilitation and to vacate acute hospital beds. There is then a pressure on the community hospital to increase their discharges to make space for more acute patients. This tension between organisational structures was clearly felt by therapy staff in this study, who were under pressure to discharge but also wanted to carry out effective and competent rehabilitation, which they were unable to do. The tension within the community hospital that is created by the drive to discharge is discussed further below. The level of pressure in the acute hospital was greater than that in the community hospital and was exacerbated by limited resources. A tension could be seen between the drive to discharge and the lack of resources in the community after people were discharged,

which was not helped by limited communication regarding the purpose of the community hospital and between hospital and community services.

5.3.2: Power relationships and the drive to discharge

Davidson et al (2019) highlighted the shift toward 'step down' in order to relieve acute hospital pressures, which was highlighted in the findings of my study also. The relentless push to discharge creates a power to restructure and repurpose community hospitals with no obligation to staff to explain what is happening as it is a management decision. However, the Department of Health definition of community hospitals describes them as developing 'as a result of negotiations between local people, practitioners and the NHS' (Community hospitals association, 2016, p.1). Nonetheless, it was found that the drive to discharge was influencing service provision without a great deal of negotiation with staff, who were unaware that they were no longer a rehabilitation facility, but rather a step-down facility to relieve pressures on the acute hospitals. Studies have found that the effectiveness of intermediate bed-based care in community hospital in relation to reducing hospital bed use is uncertain. One study found patient function was improved and that patients were not readmitted after three months, but that this was not sustained after six months (Healthcare Improvement Scotland, 2018). Furthermore, it may be more expensive than 'usual care'. Unfortunately, there is no definition of 'usual care' but it might mean community rehabilitation. A lack of evidence to back up intermediate rehabilitation at community hospitals will further weaken its position and leave it at the mercy of managerial demands to discharge quickly.

The drive to discharge also has the power to influence work practices. During interviews it was raised that nurses were 'task orientated' partly because of their biomedical perspective, but also due to the pressure to care for so many patients in a short space of time and with limited staff. This was in contrast to the therapists, who were keen to continue to operate as a rehabilitation ward. This created a 'them and us mentality', and silos had formed. Therapists were struggling with providing full therapy input due to the drive to discharge, and therapists were leaving as a result. Previously, when patients were admitted for six weeks, the therapists would have time to assess and treat a patient with the aim of returning them to premorbid function where possible, in other words, to regain the mobility and independence the patient had before whatever episode caused them to be admitted to hospital. However, Mae's case illustrates the dominance of the medical perspective in the intersection between the drive to discharge and Mae herself, since her goals were set by the

physiotherapist but overridden by medical goals. The physiotherapy goals were to increase mobility and independence to premorbid level, but these were abandoned when the patient was 'medically fit for discharge'. The power in the managerial drivers is illustrated in the drive to discharge that disregards the relationality of Mae's living environment, because if Mae is not mobile enough she will be asked to leave her residential home. The study findings suggest that it does not appear to have been communicated to therapy staff that they need to adapt a new paradigm that is faster and has less time for rehabilitation. Furthermore, it may need to be communicated that the community hospital is no longer a 'rehab ward', and that rehabilitation will occur in the community. Equally, the study suggests that this change of role and purpose has not been communicated to the community either as patients are waiting several weeks before rehabilitation commences. The impact on a patient like Mae, who has no family and is reliant on care home staff who have a policy of no more than assistance of one to mobilise and toilet, could be that she would be forced to leave her home that she loved.

Health professionals were feeling powerless against the drive to discharge, but in health professional/patient interactions the drive to discharge provides the health professional with the power. The drive to discharge is therefore both disempowering and empowering at the same time. Policy and procedure that benefits the drive to discharge becomes the overriding power. Alastair's case is an example of health professionals and the drive to discharge pushing through for a discharge home even when his daughter was adamant he could not cope and was not safe. Health professionals used policy concepts of choice and capacity – the patient has capacity to decide to go home and it is his choice to go home – to override and ignore his daughter's legitimate concerns based on her experience of caring for her father and photographic evidence of self-neglect and lack of support from community services. Alastair's daughter did not live nearby so was reliant on care agency and community nurses, but she felt regularly let down by these services and Alastair had repeated hospital admissions and discharges home. Alastair's daughter felt so overwhelmed by the power of the drive to discharge and the health professionals perpetuating it that she felt it necessary to involve the local member of parliament. The marginalisation of her point of view combined with concern for her father made the situation stressful and upsetting. This is discussed further in Section 5.6.3 below – the drive to discharge/carer intersection.

The drive to discharge also has power over community practices, without communicating with the community services. The drive to discharge created loss of trust, suspicion and

criticism from community health professionals. For example, Zoe's community occupational therapist especially felt that the hospital occupational therapist could not have possibly investigated all the home hazards and was only intent on quick discharge, which was not correct. However, each had a different idea of what acceptable risk was. The hospital occupational therapist, with the pressure to discharge, felt Zoe had lived a long time in poor conditions and could therefore return to them. However, the community occupational therapist, with no pressure to discharge, was keen to readmit Zoe to a 'place of safety', which was the community hospital, due to the poor living conditions. Recent behaviour during the 2020 coronavirus pandemic will only reinforce these views that the hospital staff do not care and are only trying to achieve discharge. The government's reaction to the pandemic, which is ongoing at the time of writing, was to speed up the discharge conveyor belt to make room for COVID-19 cases. Six months on, people are now questioning the UK government's initial response, which was to speed up the discharge conveyor belt, particularly for older people in care or nursing homes. In an article in *The Guardian* (Savage, 07 June 2020), Savage reported that a letter was sent to care providers from NHS England and the government on 19 March, which aimed to free up hospital capacity and ordered 'the safe and rapid discharge of those people who no longer need to be in a hospital bed. The new default will be discharge home today' (para. 7). Therefore, the pandemic sped up the drive to discharge as hospitals struggled to balance the priorities of discharge in order to create space for COVID-19 positive patients whilst protecting the care sector. Unfortunately, coronavirus testing was not readily available for staff or patients at the time and the suspicion is that older people were discharged back to care homes with the virus, where it spread and caused many deaths of patients and staff (Savage, 2020). This raises ethical issues regarding the treatment of older people when healthcare is being rationed and may indicate a wider issue concerning inequities faced by older people. Furthermore, the push to discharge people back to their care homes without testing undoubtedly put other residents and their carers at risk of harm, with care home workers 'literally putting their lives on the line by going to work', which was compounded by a lack of personal protective equipment at the start of the pandemic (Samuel, 2020, para. 5).

This section has provided some context of the discharge element of Figure 15 and the tensions within it. The following section will look at what is happening in the 'older people with frailty' element, and then the intersection with the drive to discharge.

5.4: Older people

In Figure 15 the 'older person living with frailty' element is complex in itself, before coming into contact with the health and social care systems and increased reliance on family. This section aims to ground the analysis in the societal context of ageing and dying, and the biomedicalisation of ageing, in order to understand the intersections and forces already at work before coming into contact with the drive to discharge.

5.4.1: Societal context of ageing and dying

Old age is different to most other intersecting inequalities because we all age eventually and as a result will experience both the negative and positive aspects of age relations during a lifetime (Calasanti & Slevin, 2006). The intersectional framework encourages the consideration of the context of older people living with frailty who are approaching the end of life in an ageist society. Ageism plays a significant role in shaping the experience of older people at the end of life (Gott et al, 2011). Gott et al (2011) reflected on the lack of integration between gerontology and palliative care in 'inherently ageist' societies that place greater value on youth. They refer to previous studies that highlight how palliative care is oncology-centric, but note that even older people with cancer receive less hospice care than younger people, whether it is inpatient or outpatient. They cite a significant body of research which shows that older people experience unmet physical and psychological symptoms at the end of life and draw attention to the fact that there is little evidence that the current configuration of specialist palliative care would meet those needs. Furthermore, older people are treated as a homogenous group who are more accepting of death, and their death invokes less anger or injustice than the death of a younger person. This attitude also means that older people are perceived as requiring less support, because death in later life is seen as 'natural' and is used as a basis for rationing limited palliative care services. Rationing is carried out by health professionals who are gatekeepers to specialist palliative care services, as evidenced by the fact that those over 65 are offered a narrower range of services. Gott et al (2011) reference the evidence that health professionals' ageist beliefs influence referral decisions and the mindset that it is 'just old age' symptoms that do not merit care, which in turn further justifies ageism. They discuss how the social construction of old age is negative, with dependency and mental and physical infirmity being a dominant discourse. They argue that this has an impact on old people themselves, as well as influencing other people's approach to them. Society rejects the failing older body; age relations are a system of inequality, whereby old age is a disadvantaged status. People

internalise these notions of old age in early life and carry them as they age (Gott et al, 2011; Calasanti & Giles, 2018), which influences decisions later on in life.

The intersectionality paradigm illuminates the 'complex ways in which people's experiences over the life course and in old age emerge from the intertwining of their various categorical memberships within systems of inequalities' (Calasanti & Giles, 2018, p.70). Furthermore,

> *Old age is more than just the cumulative impact of other statuses over the life course; it is a political location. Those marked as old lose authority and power, including over their bodies; they are marginalized in the workplace, losing status and income, and they are stigmatized and culturally devalued. To be old is to be socially excluded from full citizenship.* (Calasanti & Giles , 2018, p.71)

Gott et al (2011) conclude with an intersectional perspective highlighting the fact that ageism operates in other spheres of life, which combine with 'cumulative disadvantages' over the life course. Examples given include difficulty accessing adequate housing and financial resources and the physical environment. These can influence end of life choices, including (in opposition to policy) the desire to not die in a home that is inadequate. They refer to the 20,000–50,000 older people who die of cold-related illnesses annually in the UK in order to highlight the conflict between the 'home is best' policy and the reality that older people face. Seven years later, Pollock and Seymour (2018) continued to raise the issue of palliative care provision that does not align with the needs of older people dying with frailty. Additionally, they noted that the 'good death' construct constrains patient choice as it does not reflect patient values. They call for new models of palliative care to accommodate diversity, with need rather than diagnosis being the basis for its provision. The emphasis on diagnosis rather than need points to issues regarding the biomedicalisation of old age and death.

The intersectional perspective has looked at context but also illuminates the power dynamic between older people and society: 'Old age not only exacerbates other inequalities but also is a social location in its own right, conferring a loss of power for all those designated as "old" regardless of their advantages in other hierarchies' (Calasanti & Slevin, 2006, p.5).

Older people experience a loss of power and are encouraged to deny old age, to be ageless. However, we can deny that we are ageing, but when we are 'forced to confront the process', as with frailty and failing body, 'we treat it as ugly and tragic' and a failure (Calasanti & Slevin, 2006, p.5).

5.4.2: Biomedicalisation versus relationality

The biomedicalisation of ageing constructs as well as problematises ageing, as a medical problem or 'pathology' that is therefore viewed through a medical lens as a clinical phenomenon with clinical problems that need to be managed (Kaufman et al, 2004). The biomedicalisation of ageing also has an influence on public opinion on ageing, 'fostering the tendency to view aging negatively as a process of inevitable decline, disease, and irreversible decay' (Kaufmann et al, 2004, p.594). Medicine is considered the right, and only, tool for managing the problems of ageing, where medical intervention is normalised as necessary and appropriate:

> *Other ways of defining aging and conceptualizing its problems and solutions are muted or are inconceivable. Convinced that only biomedical science can save them [i.e., older people], the solutions to the problems of aging appear resolvable by the purchase and consumption of more and more high-cost medical services and technology.* (Kaufmann et al, 2004, p.594)

Under the biomedical model, old age is seen as 'a process whereby the outcomes of social factors are defined as medical or personal problems to be alleviated by medical intervention' (Calasanti & Giles, 2018, p.6). Death also gets a similar treatment, with the biomedicalisation of death influencing policy discourses, which are framing the issues and has consequences for how death and dying is viewed as something that can be managed within a medical system (Borogstrom, 2015). Within this context death is also viewed as a failure:

> *death is commonly portrayed and experienced as a failure within medicine and doctors may be reluctant to discuss terminal prognoses with patients and their families. Within the last decade, there have been several public discussions within the popular media about how dying people are cared for, with a perception that the NHS fails to provide people with dignity and respect as they die. Not only then is death itself seen as a failure within medical practice, but also medical professionals are portrayed as failing to adequately care for the dying.* (Borgstrom, 2015, p.704)

Twigg (2004) argues that age and ageing are not just biological, but deeply social and that this social aspect needs to be understood in order to understand the role of the body within the social construct of ageing. Essentialist biomedical or reductionist approaches dominate discourse, with the claim of presenting the 'truths of ageing' in terms of its bodily basis. Twigg (2004) makes the case for giving weight to the 'complexity and plurality of social and

cultural meanings', recognising the ways in which the body and bodily experience are constituted in, and through, discourses. From an intersectional perspective, Calasanti and Slevin (2006) state that rather than 'having to deny old age, or to strive to look young, old people should have the freedom to choose lifestyles and ways of being old that are suited to them' (p.14).

When an older person meets the drive to discharge, the power of an ageist society and biomedicalisation of old age has a huge influence, not just on how society sees the older person but how they view themselves. Furthermore, these views are reflected in policy and set up a situation where the bags on the conveyor belt are viewed as 'other' or 'less than' younger patients due to the fact that their bodies are failing. This creates a mismatch between policy and the experience of the older person living with frailty.

5.5: Older person/drive to discharge intersection

As discussed above, the drive to discharge is more than a process; it is also the product of policy and managerial forces that are influenced by the biomedical model view of ageing and death. A bias is created in society and healthcare practices where the perception of ageing is one of decline and deterioration that disempowers older people. The tension between policy and patient is discussed further to examine the intersection of the drive to discharge and older people at the end of life. An illustrative example from the findings is also provided.

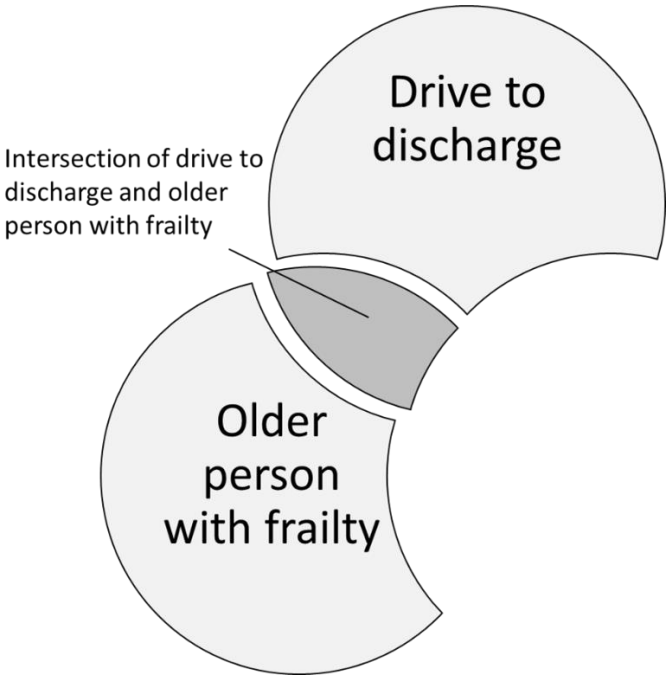


Figure 16: Older person and drive to discharge intersection

5.5.1: Policy versus reality

The biomedical perspective influences policy discourses and places emphasis on the individual's body as they age and at the end of life. It also frames the ageing/dying person as an autonomous individual and creates a 'tension operating at the discursive level which subordinates the relational and interdependent nature of death and dying' and frailty (Ellis et al, 2016, p.29). Greenhalgh and Papoutsi (2018) highlight the confusion felt by healthcare professionals due to a mismatch between policy and reality, stating that, 'Contemporary healthcare is experiencing several important challenges, including a mismatch between the "patient in the guideline" and the "patient in the bed" due to multi-morbidity and interacting sociocultural influences,' among other issues. They recommend that researchers and clinicians need to 'develop capability and capacity to handle the unknown, the uncertain, the unpredictable and the emergent' (Greenhalgh & Papoutsi, 2018, p.1089). They suggest a mindset that 'recognises changing interrelationships between parts of the system and adapts to unexpected change' in practice and research. This embracing of complexity is something that intersectionality enables; intersectionality is an ideal lens though which to view 'changing interrelationships' that are social and not just with and within the system. Furthermore, I would add that this needs to apply to patients and family, not just to the system. Ellis et al (2016) also described a tension between policy and reality, where policy rhetoric 'promotes independence, personal responsibility, active citizenship, and the right to choice and to maintain control in all domains of one's life' (p.27). As discussed in the literature, older people's preferences at end of life are complex and relational. As the policy discourse of choice, control and autonomy dominate, the relational and interdependent nature of very old age, and death and dying, get ignored. The value placed on individualistic policy also overlooks the role the carer has in enabling discharge and in allowing the patient to live in their preferred residence, as well as the 'highly complex relationships older people have with their families' (Ellis et al, 2016, p.29). The patient-carer relationship is explored further in Section 5.7 below. Age and dying are problematised by the biomedical model, and choice is framed in policy as a timely solution to that problem (Borgstrom, 2015). Furthermore, choice is seen as a goal within policy that represents a 'good death', where 'choice is deemed as a triumph over the potential for failure and lack of control that death and dying present' (Borgstrom, 2015). This is also applicable to the problem of frailty, where choice is central to 'successful ageing'. Borgstrom (2015) argues that the 'panacea of choice and control' has inhibited meaningful discussion about what might improve end of life experiences for older people generally. Choice is not only used as an indicator of 'good care'

or ‘good death’ but also as a goal of care. Therefore, choice is conceptualised as a goal as well as a solution to the ‘problem’ of ageing and death. This narrow thinking about ‘good’ or ‘bad’ old age and death has the ability to hinder the policy development necessary to understand what is different about dying in late old age. Increasing death rates due to the ageing population are projected to put a strain on institutions providing healthcare, particularly hospitals, which is where ‘most people have died within the UK over the last few decades’ (Borgstrom, 2016a). When choice is conceptualised as both a goal and a solution to the ‘problem’ of ageing and dying, failures (ageing and death) are inevitable if we live long enough, thus creating a further tension.

Borgstrom (2015) studied the reality of how choice is experienced for people at the end of life, how ‘choice’ was mobilised in English end of life care policy, and how people who may be the subject of end of life policy perceive choice. Valuable insight was gained from the perspective of the dying in terms of how ‘choice’ was perceived. It was found that elucidating choice when talking to patients about their preferences is an imperfect process that does not adequately capture their experiences as they come to the end of their lives. People struggled to articulate choice, and their expressed preferences represented the complex contexts in which care is performed. The study found that end of life choices were relational and situated in the context of social relationships and that ‘although death is certain, the possibility of control alluded to by choice rhetoric is not realised in practice’ (Borgstrom, 2015, p.700). The reality that Borgstrom’s study explicates is that patients ‘muddled through’ the healthcare system where enacting choice was more complex than portrayed within policy rhetoric. Patients felt they had no autonomy or agency and that their choices at the end of life ‘did not neatly fit into the idealistic ambitions of end of life care policy’ (Borgstrom, 2015, p.701). It was recommended that rather than just a rhetorical device, choice should be embedded in practices and policies as it is currently articulated in an incomplete way at present. Patients made choices but did not feel they were something that could be shared as the preferences would negatively change the family dynamic. This paints a picture of choice being complex, relational and subtly negotiated and shaped by social context. Literature suggests ways of using relationality to improve care/experiences. An intersectional lens brings into focus an awareness of each person’s social context, which is needed when looking at an ageing population who are increasingly living alone (Rogers & Kelly, 2011; Pollock & Seymour, 2018). The policy goal of death at home will be increasingly difficult to achieve and therefore a public health approach to palliative care may help to shift the focus from individual to relational as a way of enabling death at home, if it is desired.

The study has shown that an understanding of a person's context and the influences on their decision making are heterogenous, and a focus on death at home only serves to constrain and disadvantage, rather than enable, those who cannot or do not wish to conform to the choices made available by the system. As we saw in the findings, concerns regarding the welfare of pets can be a driver for making significant decisions that affect both the patient and their carer, who has no say in this decision. The literature highlights that dying and ageing are relational and that a relational approach is therefore required, such as the public health approach of compassionate communities or cities (Gott et al, 2017a; Kellehear, 2005). Kellehear describes compassionate cities as an 'intersectorial' approach to public health, where health depends on intersecting elements and health is not simply the absence of disease (2005). Compassionate cities provide a public health approach to end of life care that is inclusive of experiences of dying, death and loss. 'Community' has been viewed by palliative care as the 'general public', rather than a set of specific networks 'that are capable of sharing the burden of care in practical ways beyond members of a family' (Kellehear, 2005, p.49). The compassionate cities concept is relational and views individuals in their community and is therefore truly holistic. Gott et al (2017b) identified that communities could play a particular role in reducing social isolation and loneliness among people of advanced age prior to death. Public health approaches to palliative care are recommended, but they require social networks being built around people who are dying and their family carers (Gott et al, 2017b). Such strategies also need to be flexible enough to be responsive to the unique end of life circumstances of the very old. However, Gott's study found that there were barriers to network development and no evidence of new social networks being formed at the end of life. There is little evidence that community help is forthcoming and again it falls to informal carers. Carers highlighted that they would like someone from a community network to sit with an older person but that people were too busy. This is possibly where a death doula role could be beneficial to both the older person and their carer. A death doula or midwife is someone who assists a dying person much like a birth doula or midwife. The role is to support the dying person and their family emotionally, spiritually and physically. Many are volunteers who feel strongly about creating a 'safe space' and are a neutral third party outside of health and social care services. This volunteer model could be applied to older people living with frailty if frailty were to be considered an end of life stage as per Seymour (2017). Locally to this study there is a model under development called ESTHER; it encourages clinicians and care professionals to ask, 'What is best for Esther?', a fictitious patient, to ensure person-centred care. User involvement is

integral to the model, building a network around Esther, including family, friends and key staff from health and social care (KCC, n.d.). At present this is in the pilot phase.

Pivodic et al (2020) carried out an analysis of public policy documents from 13 countries with rapidly ageing populations. They found that regarding the care of older people, integration of palliative care is insufficient and that healthcare policies for older people need revision to include reference to end of life care and dying and to ensure that there is a link to existing national or regional palliative care strategies. They argue that the existing strong policy aims for older people, such as care coordination and continuity, communication and care planning, and care for family, are an opportunity to highlight the possible contributions of palliative care towards achieving these aims. The integration of palliative care into care of older people would have benefitted participants such as Amy and her daughter, who felt that she and her mother were not being supported sufficiently because her mother was not dying in the right way to get hospice input, namely from frailty rather than the breast tumour. Perhaps this is because other policy priorities for older people are focussed on 'successful ageing', which is discussed in the next section. The literature supports a shift in how death in older people living with frailty is perceived in policy. Covinksy et al (2003) say that patients with advanced frailty are poorly served by end of life care systems that are historically targeted toward patients with cancer. The literature has highlighted that frail older patients dying slowly from complex multiple morbidity have changing needs, experiences and expectations and that these have moved out of alignment with the organisation and ideology of palliative care (Pollock & Seymour, 2018). The prolongation of dying creates enormous new challenges throughout all levels of society. My study found that only those with cancer as well as frailty were referred for palliative care, even though all ten patients had been identified as possibly dying in the next six months due to their frailty. Therefore, older people were not recognised as dying unless they had cancer. To accommodate older people living with frailty who are approaching the end of life, a new way of thinking/working is required. Teggi (2018) recommended a longer time perspective of dying in old age and referred to the Scottish trajectory model of end of life care delivery (Figure 17) as it 'has the potential to handle more unpredictable dying trajectories' that are typical in frailty. End of life care policy and practice need to respond to the evidence that dying in late old age is different from dying from cancer at a younger age. 'Given old age death's uncertain timing, only a positive and shared expectation of dying can enable end of life care to take place at the end of a long life. This is also the founding stone of the English

end of life care policy promoting patient's choice and family involvement in end of life care' (Teggi, 2018, p.119).

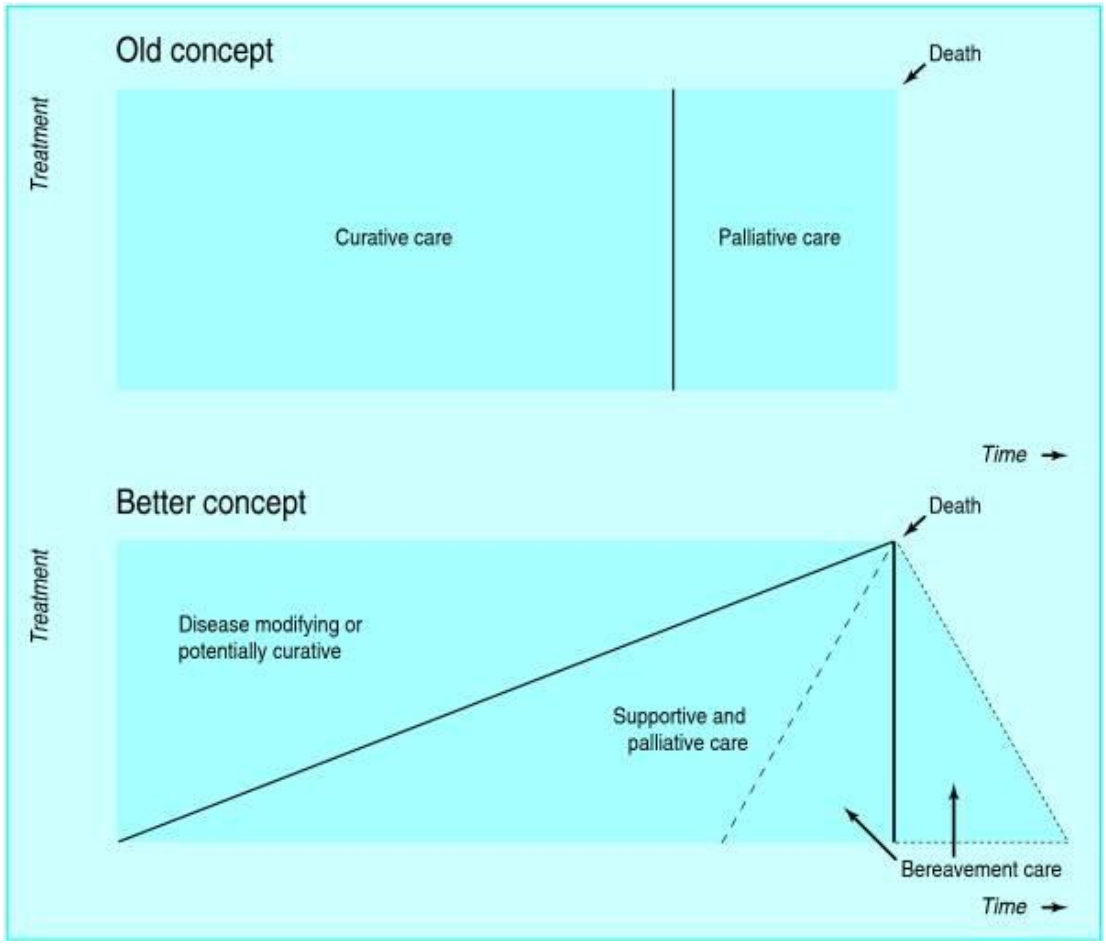


Figure 17: Murray et al (2005) Introduction of palliative care with time as disease progresses

There is a growing emphasis on the palliative needs of older people living with frailty. The British Geriatric Society (2020) has produced clinical guidance for geriatricians regarding the end of life needs of older people saying that 'severe frailty is an end of life state and should trigger healthcare professionals to identify and sensitively discuss end of life needs and preferences'. However, it goes beyond advocating care planning alone to explain that 'clinical uncertainty accepts and manages the inherent uncertainties of living and dying well with frailty'. The focus is moving from identifying dying to a focus on parallel planning, where there are several possible outcomes across specialities, some becoming more obvious over time and some less likely. The guidance acknowledges that both recovering and dying are possible outcomes. They recommend that clinical teams and specialities should work together with the person and their family with the understanding that dying or recovery are equally possible. This requires an integration of palliative ways of working with geriatric

medicine that encourages shared and active decision making. The guidance states that family and social carers should be included and suggests that they use a tool to map the incremental changes in a person's condition and frailty over time. The tool should prompt an appropriate response from health professionals and it is hoped that this will help everyone to engage with clinical uncertainty and identifying end of life, whilst allowing for an optimal clinical response and 'gives the older person and their family a sense of security and control despite the changing condition. It enables older people with frailty both to live and to conclude their lives well' (BGS, 2020). Such a tool would encourage all stakeholders to be involved in the process and would enable the tracking and management of health changes, which would support the carer, who would be in charge of the tool day to day. It is an approach that is not an either/or but a both/and, as per the intersectional framework; the older person is living with frailty but also preparing for dying; nevertheless they can carry out rehabilitation to stay as independent as possible, but may deteriorate quickly. The tool would require someone to feedback to, who would then action appropriately. Social workers are ideal for this sort of role, but are not currently utilised with older people at the end of life (McNamarra & Rosenwax, 2010).

Integration would also lessen the power of the drive to discharge as patients are not being passed from one service to another. This would also improve trust between hospital and community professionals. The Torbay Care Trust is an example of integrated health and social care teams using pooled budgets to provide a range of intermediate care services and supporting hospital discharge. Health and social care co-ordinators help to 'harness the joint contributions of team members' and the results include reduced use of hospital beds, low rates of emergency admissions for those over 65, and minimal delayed transfers of care (Goodwin & Smith, n.d.). At the very least, communication regarding the change in purpose and use of community hospitals needs to be communicated to patients and carers, as well as hospital and community health professionals, in order to stop the mismatches in expectations and rebuild trust. Community services also need clear communication of hospital expectations regarding rehabilitation input in the community. A frailty pathway would prevent patients falling through the cracks and waiting several weeks for rehabilitation. A single point of coordination would ensure that people did not fall through the cracks and relieves the burden on carers. Such a role could also facilitate compassionate communities' input to support older people and their carers. In the absence of integration, the embedding of palliative care into the system would enable a flexibility when treating older people living with frailty. Bone et al (2016) conducted focus groups with older people

and carers to develop a model of community-based episodic short-term integrated palliative and supportive care (SIPS). Stakeholders felt that the model could be beneficial, but disagreed on the timing of intervention, and Bone et al (2016) highlight the importance of including stakeholders in service development.

5.5.1.1: Neoliberalism and successful ageing

Ellis (2016) summarises policy priorities as follows: 'independence, personal responsibility, active citizenship, and the right to choice and to maintain control in all domains of one's life' (p.29). This is a neoliberal ideal as the 'fundamental tenant of neoliberal policies is the ability and necessity for an individual to make choices' (Borgstrom, 2015, p.701). This assumes that patients will favour themselves and promote their own lives but as we see above choices are contextual and relational. Neoliberalism has gained popular and political appeal since the 1990s, with an increased emphasis on individualistic patient autonomy within the NHS. The ideal is that healthcare professionals and patients work together to decide a patient's treatment. Furthermore, service provision is to iteratively change in response to population and patient preference and needs. Choice is seen as having the ability to improve patient experience and reflects a shift towards consumerism and neoliberal values in healthcare policy. Neoliberal healthcare policy views patients as 'users' of the NHS empowered through their choices, rather than passive recipients of care (Borgstrom, 2015). Rubinstein and Medeiros (2015) define neoliberalism as:

> *predominantly associated with the ongoing shift from public to private ownership that began in the early 1980s; the shift of risk from the state or government to the individual; the continuing attempt to downsize or privatise established social care; the changes in governmental support for health and well-being; the increasing income inequality; and, most significantly, an increasing focus on the individual as the locus of social action and motive.* (Rubinstein and Medeiros, 2015, p.3)

Neoliberalism's focus on choice, rather than society, as a way of governing, ties in with the biomedical problematising of frailty, where successful ageing is seen as a solution. Successful ageing has a heavy reliance on the neoliberal concepts of choice and autonomy. The successful ageing paradigm was established by Rowe and Kahn (1998) and focused on three components of wellbeing: 'low probability of disease' and disability, 'high cognitive and physical…capacity, and active engagement with life' (1998, p.433). It relies heavily on the realm of individual action as the 'primary motivational principle for the achievement of successful ageing' (Rubinstein & Medeiros, 2015). Rowe and Kahn proposed that successful

ageing 'can be attained through individual choice and effort' (1998, p.37). The book does not take into account the personal economic, social, cultural or political intersections that will have influenced how a person ages or how their life and circumstances may cause ageing sooner than the book may predict. For example, Colich et al (2020) found that children who suffer trauma from abuse or violence early in life showed biological signs of ageing faster than children who have never experienced adversity. Colich et al (2020) examined three different signs of biological ageing: early puberty, cellular ageing and changes in brain structure. They found that trauma exposure was associated with all three. Within the successful ageing paradigm there is no room for this level of complexity and intersection that influences the determinants of health. Therefore, if you age unsuccessfully it is your own fault due to the bad choices you made. Furthermore, you have not tried hard enough because 'successful ageing is dependent on individual choices and behaviours. It can be attained through individual choice and effort' (Kahn and Rowe, 1998, p.38). This suggests that you cannot age successfully in the presence of disease and rather overlooks the inevitability of decline before death. The pervasiveness of the concept of successful ageing can be seen in documents such as a Healthcare Improvement Scotland document entitled 'Living well in communities with frailty. Evidence for what works':

> *Frailty is a manifestation of ageing that is associated with poor outcomes. A person with frailty can experience serious adverse consequences following even a relatively minor illness … timely identification of frailty, and targeting with appropriate evidence-based interventions, can help to reduce the likelihood of progression of frailty and poor outcomes and support the long-term management of people's health and well-being.* (2018, p.4)

In keeping with the idea of successful ageing, the document is about promoting wellness and choice, but skirts past the fact that frailty is leading to death. There is an emphasis on interventions to delay the progression of ageing and frailty and little consideration of how end of life should be managed and how relational aspects should be taken into consideration. Calasanti and Slevin (2006) critiqued successful ageing from an intersectional feminist perspective. They propose that the assumption regarding staying fit is not as simple as portrayed by successful ageing. It is 'highly valued capital' and requires the maintenance of activities popular among the middle aged who have the privilege of money and leisure time. Calasanti and Slevin (2006) argue that successful ageing means not being old or ageing and not *looking* old. With society's emphasis on being or appearing youthful, the body

becomes central to the identity and to ageing, with increasing levels of work required to maintain a youthful appearance. Calasanti and Slevin (2013) use intersectionality to highlight that 'class, gender and racial biases embedded in these standards of middle age emphasise control over and choice about ageing' (p.13). The construction of old age contains little that is positive, with fear and disgust of growing old being widespread. The failure to age successfully is then a personal failure, with frailty being the ultimate failure. The neoliberalist successful ageing paradigm with its emphasis on choice and control, together with biomedicalisation of age and death, are reflected in policy that has an impact on older people with frailty who are approaching the end of life, with recommendations about exercise to ward off frailty but little about when frailty inevitably leads to death. Once again, older people become a marginalised group who are portrayed as a burden to society and the healthcare system. The policy push for successful ageing in one's own home does not account for a lack of resources in the community which, as seen in the findings, means there is a three or four week wait for rehabilitation, and does not allow for choice if a patient feels safer in the hospital or recuperative care due to a lack of a social network. Fundamentally, '"choice" cannot control the uncertain ways in which dying processes unfold', or how frailty will dwindle (Borgstrom, 2015, p.708). A practical tool for discussing, capturing and meeting end of life choices is the advance care plan. In policy it is considered to be important for these purposes, but studies have shown how setting, relative health status and relationships affect the preferences people express (Seymour et al, 2010). Borgstrom cautions that the practice of advance care planning 'should not be so readily conflated with the idea of individual autonomy, assuming that they both have the same material and meaningful consequences for people's experiences of dying and death' (Borgstrom, 2015). Individuals with an advance care plan are more likely to die in their preferred place of death, with increased shared decision making as well as improving patient and family satisfaction with care. However, the evidence is limited regarding advance care planning regarding a reduction in emergency hospital admission and in improving patients' quality of end of life care (Healthcare Improvement Scotland, 2018). Therefore, advance care planning has its merits, but it is not a plaster to fix the issue of older people having inequitable end of life experiences to those younger than them. There is scant literature on what intervention or ways of working would improve the end of life experience for older people, specifically with frailty, and their carers. An illustrative example of the older person/drive to discharge intersection follows which highlights the illusion of choice created by the drive to discharge and the powerlessness of the patient to assert their choice.

5.5.2: Illustrative example of the older person/drive to discharge intersection

Hazel was living at home until the age of 100. She had a stroke and was admitted to an acute hospital then transferred to a community hospital. At the community hospital they were unable to rehabilitate Hazel to her premorbid mobility or independence. In fact, she was nursed in bed because she was susceptible to pressure sores. The rehabilitation goal at the community hospital became independent feeding. As Hazel now needed to be nursed in bed, her needs were considered too high for social services to care for her in the community, particularly as she had no social network other than her 92-year-old brother-in-law. Hazel had no children and was a widow. Nurses discussed with Hazel how her needs had changed and she could not be supported to live at home, and felt they had had agreement from Hazel about moving into care. However, if Hazel had insisted on going home a meeting would have been called where it was outlined to Hazel all the reasons her needs were too great to go home and be cared for by health and social care services. During her interview Hazel said that it would be 'heaven' to go home – she did not want to be in care. The 'choice' presented to Hazel was to choose which care home. Going home was not an option and therefore Hazel was presented with a 'double bind' whereby the illusion of choice was given but was not really a choice at all (Bateson et al, 1972). This concept ties in with the intersectionality concept of fairness within social justice, whereby rules appear to be equally applied to everyone but produce unequal and unfair outcomes. Older people such as Hazel are unable to even see their home one last time and are transported straight from hospital to a care home. During the interview her nurse commented that it was 'harsh' to not be able to see your home again. The older person has failed to 'age successfully' and has become a burden and is treated as such. Furthermore, the policy push for patient choice overlooks the carer's role. Hazel's care home manager, during the interview, commented on how stressed the family are when they are given a week to find a care home for their loved one. They are given a short period of time to decide on their loved one's permanent and final step down in health and step up in frailty and dependence. Owing to means testing, Hazel had to self-fund her placement in care, and her next of kin was expected to find a home and arrange for her placement. Hazel's 92-year-old brother-in-law chose the cheapest home, which had no nursing care, as he thought that looking after her funds was the best way to judge which home was appropriate. Due to a lack of nursing care on site and communication from the hospital Hazel was not cared for in bed, her pressure sores opened up and she died. The carer was unsupported and ill equipped to make such an important decision, and Hazel did not have her health or psychological needs met.

The deficit between the patient in the bed and the patient in discharge policy means that the push for older people's wellness does not take into account that older people living with frailty are approaching the end of life. However, if the older person is not well enough they are consigned to a care or nursing home that may not be equipped to deal with their needs. The power of the drive to discharge overpowers individual agency, and although health professionals knew they wanted to do what was in the best interest of the patient, they could not. The illusion of choice is presented in order to claim a 'good discharge'. Therefore the drive to discharge is dehumanising in its constant push and assumptions regarding the ageing body and successful ageing. Care is based on the notion of choice and control, but sadly it is not the reality. Defensive dehumanisation in medical practice is a concept in healthcare that is related to the self-preservation of health professionals who put the needs of the system ahead of the needs of the patient (Vaes & Muratore, 2013). I propose that hospitalised older people living with frailty could be considered to be suffering if viewed within the context of society and policy outlined above; for example, failed, a burden, body is letting them down. Defensive dehumanisation is a way for health professionals to cope with the emotional demands of caring when someone is considered to be suffering, thus reducing the risk of burnout. Examples given by Vaes and Muratore (2013) of ways to dehumanise the patient include the use of medical language to describe a patient and a lack of engagement with the patient's broader lived experience. This may explain why health professionals are not engaging with relational aspects of patient and carer lives when planning discharge. Defensive dehumanisation paints a picture of health professional as purely aiming for self-preservation. However, the concept of 'moral distress' helps to place health professionals within complex clinical contexts, in this case within the drive to discharge (Gallagher, 2011). Moral distress has been found to,

> *affect the health of nurses and their provision of care, job satisfaction, and retention. Nurses who experience moral distress have reported physical symptoms, such as headache, neck pain, and stomach problems. Psychological and emotional symptoms include anger, guilt, depression, frustration, and feelings of reduced self-worth*. (Gallagher, 2011, para. 9)

Ethical values guide the practice of health professionals, their behaviours and their treatment of patients. Moral distress is caused by poor-quality and futile care, unsuccessful advocacy and raising unrealistic hope (Gallagher, 2011, para. 7). This can be found in the case of Hazel's nurse, who used the 'scaling' described in Section 3.5.1 to differentiate

between the operational success of the discharge and how she felt personally or professionally about it. She used the word 'harsh' to describe the lack of choice and control afforded to older people who are admitted from home but discharged to a nursing home. In their study, Camp et al (2018) found that medical students described in their reflections greater ethical challenges and more moral distress when dealing with geriatric patients rather than younger patients. Themes regarding death and dying were also more prevalent in reflections regarding geriatrics. Deschenes et al (2020) propose the use of relational ethics for navigating the day to day 'ethical moments that occur between people' by examining these situations through the 'core elements of relational ethics: mutual respect, engagement, embodied knowledge and interdependent environment'. Deschenes et al (2020) suggest that when attention is paid to the quality of relationships, one must 'focus on the kind of relationships that allow for the flourishing of good rather than evil, trust rather than fear, difference rather than sameness, healing rather than surviving and so on' (p.770).

An illustrative example from this study of dehumanisation (and possibly the avoidance of moral distress) was when Ivy was readmitted to hospital after a failed discharge home. The healthcare assistant asked if Ivy was 'just playing up', as she had done so well on ward but so badly at home. In this instance the failure to get to bottom of complex dynamic between Ivy and her daughter and the resentment felt regarding her daughter's mother-in-law living at her house. In the interview it became apparent that Ivy was extremely resentful that she was the one expected to go to a care home, when her daughter cared for her mother-in-law at home. The casting of older people as naughty children is common and was described by Mae's community physiotherapist. She described how care home staff did not want to engage with the physiotherapy care plan and preferred to concentrate on the care home tasks and care plans that were focussed on managing bodily issues such as toileting, washing and feeding so that once again the ageing body is brought back to purely its bodily processes and choice/control are removed in favour of the system needs. A relational perspective in such circumstances would enable health professionals to view the patient as an autonomous individual situated within a social context with mutual interdependencies that influence a person's life and decision making, which could be described as 'relational autonomy'. The autonomy cornerstone of the four-principles of bioethics needs to be reconceptualised to include relationality when treating older people living with frailty in order to ensure ethical decision-making processes. Relational autonomy is discussed further in Section 5.6.3 from the perspective of the carer. It is important for the drive to discharge to take into account that older people are often isolated and that their carers are isolated too: 'Care can be an

isolating experience leading to disengagement from the carer's own "outer network" and community' (Gott et al, 2017b). Holloway (2009) described frailty as a phase of life in which increasing frailty combines with chronic and acute health problems, which is followed by a liminal state before death that the very old experience where they are 'gradually separated off from the living and the boundaries of life and death are no long clear-cut, raising considerable legal, ethical, social and moral dilemmas' (p.714). Holloway (2009) recommended social workers as the very old reach the end of life, which could also benefit carers by taking up some of the burden of advocacy and by empowering patients and their carers. Professionals such as social workers could also help to mobilise community networks that would enable the community approach to managing death and dying. The goal of this role would be ensuring quality of life for older people by embracing quality and equality of dying, which ties in with the intersectional framework. A role such as this, relieved of biomedical bias, could be more open to challenging ageist and gendered assumptions that patients and carers are subjected to, as well as enabling real choice for both parties. Their knowledge of health and social care systems could lessen the burden of navigating complex systems. They could offer a more nuanced approach, which recognises that some carers are more vulnerable than others to burnout and the complexity around why that might be so (McNamara & Rosenwax, 2010). Other studies have recommended a coordinator role (MacInnes et al, 2020). It is not a role currently utilised in the over 75s service in this locality, which the HUB meeting is part of. The HUB is a multiprofessional meeting, which reduces silo working but does not involve the patient or carer in decisions and is biased towards care at home regardless of patient and carer preferences. A professional who is purely advocating for patients and their carers, and whose major concern is not medical issues but relational, would provide a voice to patients and carers in these meetings.

This illustrative example illuminates the drive to discharge/older person intersection from this study regarding choice and control in frailty and there is literature that reiterates the issues raised and/or suggests ways of improving outcomes. The contrast between neoliberal policy that assumes autonomy and the reality of a patient's experience has been explored. The experience of the informal carer will be examined in the following section.

5.6: The informal carer

The informal carer of the older person living with frailty was found to be an intrinsic element in the discharge process and is therefore included in Figure 15. The older person is reliant on their informal carer for facilitating discharge and also for allowing them to remain in the

residence of their choice, particularly if that is their own home. The intersection between the older person and their carer is not simply an overlap. The qualities contained within the intersection have a significant impact on the discharge and the experience of the older person and their carer. As per the intersectionality framework, this section will begin with putting the informal carers into context. Ageism and sexism that older people are subjected to is also experienced by their carers:

> *As with other systems of oppression, people tend not to see the importance or contours of age relations when they are privileged by youth, even if they are disadvantaged in other ways. As a result, age relations have often served to penalise aging women or their advocates … pushing aside their work and their concerns or simply ignoring them.* (Calasanti & Slevin, 2006, p.9)

In this study the carers were overwhelmingly female and included five daughters, one niece, one family friend and one neighbour. Eight out of the ten older people/patients were also female.

5.6.1: Gender

There are currently over 5.7 million informal carers in the United Kingdom and half of those are caring for someone over the age of 75 years old. Of these, 3.3 million are female; and of those doing 20 hours or more of care a week over 60 per cent are women. With the predicted increase in population aged 80 and over and the link between ageing and dependency, it is likely that the number of carers will also rise (Lyonette & Yardley, 2003). It was a major finding of my study that carers of older people being discharged from hospital were 'intrinsic' in discharge and supporting living at home after discharge. The literature shows that early involvement of the carer is important to the discharge process and highlights how care is subtly negotiated between patient and family, and that ageing and dying are relational. This study was consistent with other research regarding the gendered nature of care, with eight of the ten patients being cared for by a female. None of the patients had a living spouse, but one had a partner who did not live locally and provided no practical support.

Williams et al (2016) looked at the intersection between gender and caregiving and found that the expectation by women themselves was that women will provide end of life care, even when experiencing considerable burden; this 'is an unacknowledged outcome of gender norms that contrast women as caregivers' (p.223). It is considered to be 'natural' that women will assume the role, and this belief is also held by health professionals as was

seen in the study with the unquestioning assumption, for example, that Jane's neighbour would provide round-the-clock care in between care calls. A key concept of Hochschild's (2003) work is that women do more 'emotional labour', such as caring, than men because of unequal power dynamics. In my study there was a lack of support from male members of the family, which was commented upon by participants. The emotional labour includes listening patiently and enthusiastically, giving advice and nurturing. Many see these activities as just another part of being a woman, but Hochschild's view is that the reality is that women need to do these things in order to make up for their inherent disadvantage when it comes to power and status. This is shown in workplaces, where emotionally laborious jobs cover half of the jobs done by women, but only a quarter of those done by men. The strain of the emotional labour is evidenced in the literature where studies found that female caregivers faced a greater incidence of mental strain than both male caregivers and non-caregivers. The strain is exacerbated by the supressing of emotions to maintain a pleasant and socially acceptable disposition and the mental strain is linked to depression. It was found that women sacrifice their own healthcare issues in order to provide care, which exacerbates their own co-morbidities and results in women suffering disproportionately (Morgan, 2016). Although emotional labour is a central aspect of many women's jobs and the caring role, it often goes unacknowledged. This means a large part of the experience of the female carer is ignored due to traditional gender roles and power dynamics. A greater understanding of the emotional labour of female carers would enable a better understanding of the role it plays in our everyday lives. It is important to understand the stress and burden of caring, since 'women's care-work experiences in earlier life cause them greater stress than men experience when caring for a spouse' (Twigg, 2004). Women caregivers provide more hours of care than men and are less likely to accept formal support (Yee & Schulz, 2000; Swinkels et al, 2017; Pinquart & Sorensen, 2006). Signs of carer stress and not coping are often ignored until crisis point, and institutionalisation happens 3–4 months after first talking about it (McLennon et al 2010). Therefore, healthcare professionals need to be alert to the fact that if a carer is indicating they cannot continue their caring role, it may be a signal for immediate assessment and referral to appropriate assistance. Larkin and Milne (2017) looked at post-caring legacies of older former carers and found depleted savings, premature cessation of employment, as well as physical and mental health issues. Therefore it is important to take carer burden and stress into account as they are future health and social care users, and whilst they care for someone on the discharge conveyor belt, they may be on a fast track to the conveyor belt themselves.

There is a complexity to the older person/carer intersection that requires attention. Carers reporting high stress may report poor quality of relationship as a consequence of the stress felt, *not* that the stress is a result of the poor relationship. Equally there could be a similar virtuous cycle whereby those who feel higher carer satisfaction could feed back into greater perceptions of intrinsic motivations to care. The older person/carer intersection cannot be over-simplified. Lyonette and Yardley (2003) highlighted that strain is also caused when a carer perceives issues but the older person sees none. This is a common issue at discharge when a patient sees no issue with their safety at home, but their safety at home relies heavily on their family caregiver, who may not feel able to provide the care required. The literature highlights certain factors that are likely to contribute to positive or negative perceptions of the caring experience for the female carer and how these influenced feelings of stress. These included paid employment, location where the older person was living, the quality of relationship with the older person, the length of time since caring began, the level of help given to the carer, and the level of help required, which lead to carer fatigue (Lyonette & Yardley, 2003; Broom & Kirby, 2013). Inter-personal factors, such as quality of the relationship with the older person, and intra-personal, such as motivations involved in care for and older person, are also to be considered. A closer kin relationship with a parent has been shown to increased stress, and a greater sense of obligation was associated with greater burden in daughter-carers. These included feelings of guilt, duty, responsibility, lack of choice, growing dependence of older person, older person's expectation of care and the perceived disapproval of others if they do not take on the care, which is an example of societal assumptions regarding the caring role. A poor relationship with the older person also increased carer stress, with frustration linked with perceptions of the older person as negative, stubborn, resistant to the carer's efforts, or engaged in a power struggle with the carer. These feelings were observed in the study.

The influence of neoliberal policies is also subtly shifting the politics of care, with 'increasing responsibility for our own care, welfare and related decisions', which makes it more difficult to care for others (Broom & Kirby, 2013, p.500). The increasing involvement of the state in end of life care has led to end of life care no longer being the sole responsibility of family or community, with dying and caring considered to be 'situated within the realm of the State and increasingly the private sector' (Broom & Kirby, 2013). Neoliberal policy, together with 'biomedical orientations toward (individualised) physiological control' have led to a 'patient-centred' model of end of life care, rather than a 'family-centred' view. The neoliberal devolution of responsibility for 'healthy' citizens' trajectories limits individuals' capacity to

care for the older, sicker generations, with family caregiving undermined by individualised living contexts. Family are unable to adequately perform caring duties as they are constrained by work or immediate family commitments and due to neoliberal influences shifting with an increasing sense of responsibility for our own care, welfare and related decisions which makes it more difficult to provide care to immediate and extended family (Broom, 2013). The female caregiver is in a difficult situation where they are simultaneously expected to care for older people at the end of life and to care for themselves and their immediate family. All eight female informal carers had their own family commitments, with other unwell or dying dependants that they cared for. In this study daughters were found to be particularly important. There are specific issues for working-age daughters with their own family to run. Whilst most research concentrates on spousal care, Read and Wuest (2007) looked at the least well-researched area of daughters caring for parents when they are dying. They found key concepts of 'Turmoil that is emotional, relational, and societal … [and] Relinquishing is a process of daughters' gradually letting go of a lifelong relationship, as they have known it with their parents, while adjusting to a new reality in a changed family structure' (p.935). They also found that navigating systems, facing loss and keeping vigil were important aspects of daughters caring for dying parents. In Section 4.7.4: 'It's a lot to keep track of!' the GP highlighted that carers do not know what services they should be asking for and often do not know they even exist. This illustrates that the task is more than just navigating systems and administration of appointments and more than just a coordination issue. It requires an advanced level of understanding of the health and social care system that generally people do not have. The two family members that did have that knowledge were observed to be less stressed than their peers. The change in parent/daughter roles to cared for/carer was also evident in my study. Whilst my participants were not keeping vigil as such, they were on high alert at all times for things going wrong (physically or care issues) and being called on at a moment's notice to help their parent who may be in crisis. There was a great deal of stress and turmoil expressed by daughters in the study, which will be illustrated in the following section.

5.6.2: Older person/informal carer intersection

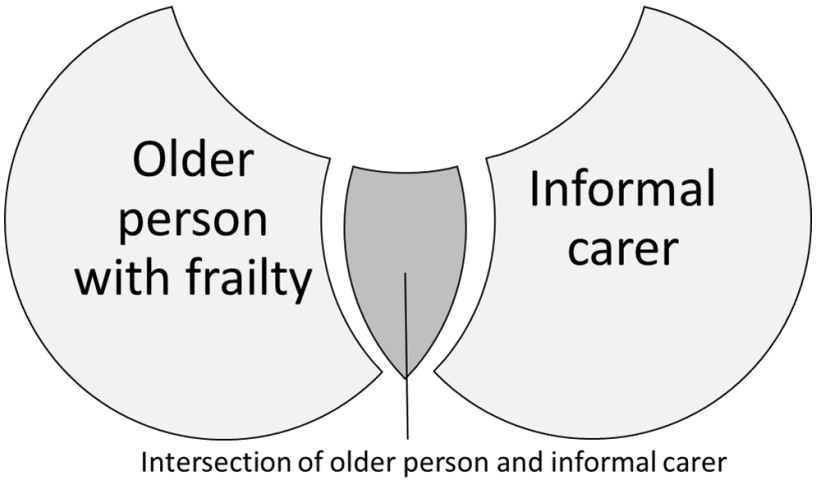


Figure 18: Older person and informal carer intersection

Stress was experienced by all informal carers interviewed, including the male carers. Amy's case provides an illustrative example of the older person/carer intersection and the impact on the carer's mental health. Amy was admitted to hospital following a fall that occurred when she tripped on her slipper standing from her armchair. She had fractured her hip and this was repaired, but whilst in hospital it was discovered that Amy had a significant breast tumour that she had told no one about. Amy was already receiving some support from her daughter but was largely independent. Amy was transferred to the community hospital for rehabilitation. The occupational therapist provided equipment for downstairs living, and Amy was discharged home after a week, walking with a frame. The occupational therapist's major input was to help ameliorate the stress and anxiety that both Amy and her daughter were expressing about returning home. She was discharged with a social care package of three calls a day to assist with washing, dressing and meal preparation. The discharge went smoothly and at interview Amy was happy with the situation and pleased to be home with her dog. However, her daughter was reporting extremely high levels of stress. The key area causing her stress was that Amy was happy to pass on concerns about her social care for daughter to sort out. Amy would phone daily to complain about her carers, which would cause her daughter to start calling the care agency, to the point where there were only three carers allowed to visit whom Amy approved of. The handing over of all responsibility was common in the study. However, it was also common for the older person to engage with services when no daughter was present and confuse the situation. For example, Amy was called by the intermediate care team to arrange rehabilitation at home in order to progress

her mobility, increase her independence and reduce the risk of falls, as per the hospital plan. However, she declined a visit and received no rehabilitation. Her daughter was unaware this had happened and had to try to restart the intermediate care input. Meanwhile, there was a constant fear that her mum would fall whilst she was not present and she would visit three or four times a day. She expressed guilt that she was not doing more, but also said that she had been signed off work with depression and her husband was dying, whom she was caring for at home. The physical burden of caring for two people at the end of life (whilst also working), being on high alert for problems and feeling guilty about not doing more, the administrative burden of organising appointments and services as well as providing transport and the psychological burden were too much for Amy's daughter to cope with. Because Amy was not dying of her tumour, the hospice were not providing any input, and her daughter found it stressful that her mother was not dying in the right way to get support.

Ivy's daughter had similar concerns regarding Ivy's safety when she was not present. She also visited daily and negotiated all health and social care issues, including non-arrival of carers and so on. Ivy's daughter went on holiday and although she has a brother who lived locally there was no one to provide the level of input that Ivy's daughter did. Ivy fell again and was admitted to hospital. At interview both admitted they were relieved the admission happened as Ivy's daughter felt she could 'finally relax' because her mother was in a perceived place of safety, although Ivy was concerned she had ruined the holiday. This ties in with Broom and Kirby's (2013) findings regarding hospice admission whereby relieving family caregivers from stress improved their capacity to be openly emotionally involved with their loved one. I feel that this is why Ivy's daughter was so keen for her mother to go to a care home; once relieved of the stress and burden of daily life she would be able to engage more at an emotional level with her mother. Amy's daughter also commented that going home rather than to a care home was not 'easier for everyone', as the hospital staff had said. The focus on patient choice ignores carer choices and needs and is discussed in the next section in more detail.

It is clear that a more nuanced understanding of the nature of care is required, one that is free of gendered assumptions, is aware of the stress created by the role and the causes of the stress, as well as the dynamic between the patient and their carer. Regarding the older person/carer intersection, it has been discussed above that family dynamics strongly influence experiences near death for both the older person and their carer. Broom and Kirby (2013) conceptualised 'dying as culturally located within a particular level of socioeconomic

development, cultural expectations, and intergenerational relations', which are important intersectional axes (p.501). Claire and Andrew's niece and daughter coped with the stress better as they felt more able to be vocal in their resistance to the drive to discharge. As a result they were labelled by health professionals as awkward or difficult. It is easier for health professionals to dismiss as awkward those powerful carers who resists the push of the drive to discharge and challenge the status quo. This dismissive approach may relate to the self-preservation through dehumanisation or moral distress discussed above. The drive to discharge is demanding that discharge happens as soon as possible, and carers who insist on waiting until the correct care home is found are slowing the process down and causing health professionals stress by slowing down the drive to discharge. There follows a discussion about patient and carer choice, together with an illustration of the drive to discharge/carer intersection in order to further investigate the intersection.

5.6.3: Drive to discharge/carer intersection

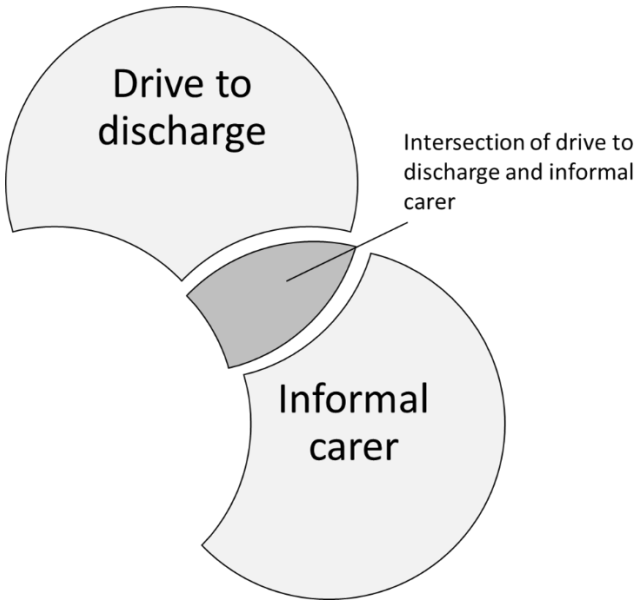


Figure 19: Informal carer and drive to discharge intersection

There is a nuance to family dynamics that is overlooked in the drive to discharge. Fisher and Lieberman (1999) looked at multigenerational family structure and found that efficient and well-structured families were less likely to admit a family member with dementia to nursing home. Significant to this study were the findings that health professionals deemed institutionalisation necessary based on 'severity and management issues', whereas family member decision making was more complex and based on the intersections of 'interpersonal, structural and emotional factors that relate to the experience of the inner

life of the family' (Fisher & Lieberman, 1999). The decision making had little to do with health professionals' 'objective' factors. Fisher et al (1999) recommended that the multigenerational family need to be part of a thorough clinical evaluation in order to provide services that are compatible with how the family operates. They argue that this would create interventions that are efficient and cost effective. Hughes and O'Sullivan (2017) called it a 'care relationship' rather than viewing the patient and carer as separate entities. Broom and Kirby (2013) described 'family centred' care that takes into account the relationality of dying preferences that are a combination of individual preference and collective desire. They recommend a focus on individual preferences and that the management of disease is augmented with a 'sophisticated and nuanced understanding of the family context', because the exclusive focus on patient choice and needs exclusively increases 'the severity of the consequences for carers' (Broom & Kirby, 2013; Procter et al, 2001). This also relates to the relational autonomy concept discussed above. It was a common theme in the study that the patient choice was prioritised as per policy, and assumptions were made about the female carers that would take up the strain after discharge. The double bind of choices offered to older people has been discussed above, but carers were given no choice about their role in the discharge and care afterward. There was a dehumanising of the carer, with an attitude of 'the neighbour will do it', with no consideration of the patient/carer intersection and the context of the carer and whether they were capable of providing the level of care required. The complex power dynamic created then is empowering the patient and disempowering the carer, with the drive to discharge having the ultimate power to keep pushing the discharge forward. The neoliberal concept of choice is used to power the discharge forward and the carer is powerless in the face of 'it's the patient's choice to go home'. This lack of carer choice also resonated strongly with the Patient and Public Involvement group, described in Section 3.8.1, which had been involved in hospital discharges as the informal carers of spouses, parents and neighbours. The literature has highlighted an 'obligate moral climate in which the role of the carer is negotiated between professionals, patients, family members, friends and neighbours and the differing assumptions about duty associated with caring roles in hospital and in family and community settings' (Proctor et al, 2001, p.206). Healthcare professionals do not challenge the patient's view of their needs or of their ability to manage their needs once they are discharged. The interpretation of the carer role by all parties centres on moral obligations and expectations, and the carer becomes defined by the social context of their relationship with the patient, rather than through personal choice. Having been defined as a carer by either the patient or the professionals, 'it was then morally

difficult for individuals … to challenge the obligations associated with the role' (Proctor et al, 2001, p.212). There is a coercive environment where non-conformity to professional expectations by the carer can lead to a sense that their moral integrity should be judged. Patient needs are privileged by health professionals due to concepts of 'patient-centred care' and the 'sanctity' of the professional/patient relationship and subordinating the need of carers (Proctor et al, 2001). The culture of the hospital creates an approach to care that prioritises the patient's definition of the care needed and reinforces an 'unobtrusive approach to family and personal circumstances and in so doing maintains a definition of caring as care-as-duty' (Proctor et al, 2001, p.215).

Recognising the independent needs of each family member or informal carer is important and can be done by acknowledging and openly discussing the moral obligations that create the dynamics of care. This can then help to produce a more appropriate context within which the needs of each individual can be acknowledge and addressed. This would ensure that carers only provide what they feel they are capable of and that they are supported sufficiently. 'Families and carers carry significant burdens in end of life care contexts and their needs often go unmet' (Broom & Kirby, 2013, p.500). Carers are feeling unsupported to provide the level of care required in order for the older person with frailty to continue living at home. If the carer's context and relationship to the patient is not adequately explored there will not be sufficient measures taken to avoid the stress and burden described above. Peters et al (2019) found that 'although participants could cite instances of good practice, the health services generally, and primary care specifically, do not currently have a strong and effective role in identifying and supporting carers. Participants cited problems of time, resources and skills' (p.648). This rang true in my study where 'support for the carer was seen as secondary to their more pressing role, responding to people's health problems' (Peters et al, 2019). The same study also found challenging levels of types and complexity of unmet need and that 'the health status and healthcare experiences of carers are poorer than comparable primary care users without caring responsibilities' (p.649). The outcomes for informal carers are therefore demonstrably worse than for other people. Unsurprisingly then, in my study carers had lost trust in the system and health professionals due to the prioritisation of patient needs, lack of support and gaps in services. Furthermore, carers had to take on a role of aggressive advocacy in order to deal with the demands of the system, push back against the drive to discharge or demand the care that was promised. These findings and analysis have shown that the carer is intrinsic to the discharge process and in facilitating the older person living in their preferred place of residence, but they are

often subject to assumptions regarding their caring role and given little choice in the matter, which raises ethical issues. From the perspective of the four principles of bioethics, little consideration is given to the carer's autonomy, which includes their right to hold views, make choices and carry out actions. The decision to discharge a patient home to their care does not involve consideration of non-maleficence, and as we have seen a great deal of psychological and emotional harm is caused, and caring can be physically challenging either from a manual handling or a geographical perspective. Consent is a key ethical concept in healthcare, which acts to 'protect patients and research participants from unwanted interventions and from coercion, abuse and exploitation' (Acott & Searby, 2012). The focus is on the patient's autonomy, protection from harm, maximising of benefits and that they are not unduly burdened. This same consideration is not extended to their carer. Furthermore, consent is an on-going process rather than a one-off event that if extended to carers would allow for changes in patient health or carer circumstances and give the carer opportunity to voice concerns about their ability to keep caring or lack of support in their role. The literature supports the involvement of carers in discharge from an early point in hospital admission (Bauer et al, 2009; Popejoy, 2011; Baillie et al, 2014; Hestevik et al, 2019). This early involvement not only allows the carer to be involved in decisions but would give them the necessary information regarding the caring role after discharge. In this sense it would uphold the concept of informed consent. When applied to patients, informed consent means that they have the right to be given all information needed to inform a decision. In this study there were frequent instances where the carer was coerced or expected to take on the role and were given minimal information about the burden that would be loaded on to them. For example, Jane's neighbour started by feeding the cat and picking up shopping. By the time of the interview, she was being called on the Life Line all day and night and was dealing with all aspects of Jane's care in between her social care visits. Justice is a cornerstone of the four principles of bioethics. Applied to this example it can be seen that due to limited resource allocation the carer is taking up a large burden. It was causing her stress and physical pain. From the perspective of intersectionality, social justice is an important concept that relates to fairness in societies where the rules may seem fair, yet differentially enforced through discriminatory practices. As we have seen, the older people with frailty are a marginalised group and their female carers are further marginalised to the point of invisibility. Unfairness occurs where the rules may appear to be equally applied to everyone yet still produce unequal and unfair outcomes. This could be applied to older people living with frailty who may need more than the standard four social care calls a day.

The consequence is a carer who is greatly burdened by filling in the cracks in services, undertaking a role they may never have consented to and have exercised no 'choice' in the matter. As we have seen above, 'choice' is envisioned in policy as improving end of life care, yet this ability to choose is not extended to the carer of the patient, which my study has found is intrinsic to the discharge and the patient living where they choose.

5.7: Conclusion

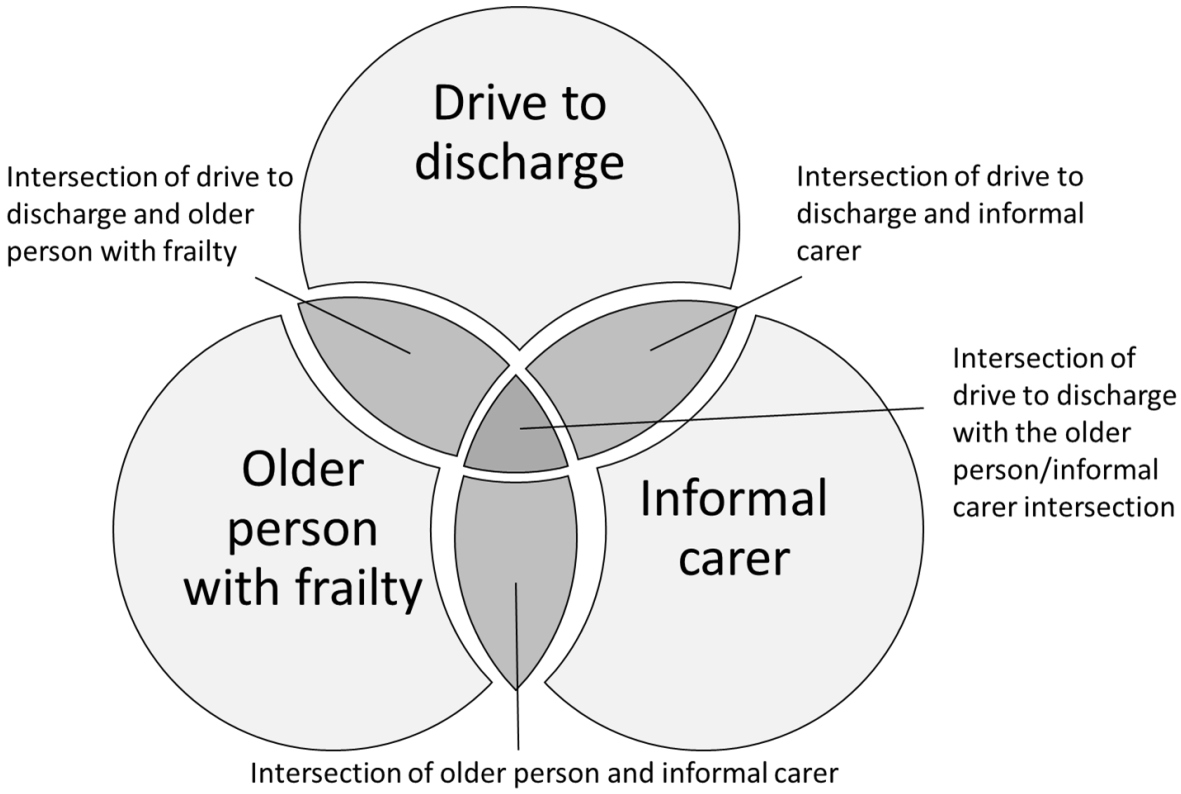


Figure 20: Intersection of drive to discharge, older person and informal carer

In the study there were no examples of a good discharge from beginning to end. At some point in the discharge process the patient or carer, more often the carer, were very unhappy with different aspects of the discharge process. The examples above have illustrated the power of the drive to discharge and how it dominates all interactions and intersections. The examples have also illustrated the power dynamic between the older person and their informal carer. The 'double bind' of choice that is offered to older people that is not really a choice at all has been discussed, but the patient's 'choice' is used by the drive to discharge to coerce carers into a caring role, presenting the carer with no choice at all. The role of informal carer for an older person is a stressful burden that requires a high level of vigilance and aggressive advocacy, whilst the older person, somewhat overwhelmed by the number

of services and health professionals, surrenders control to their carer, thus further burdening them. Feelings of guilt that they are not doing enough or failing their parent, as well as gendered assumptions regarding care and the nuance of family dynamic, provide a carer context that is complex and vulnerable. A loss of trust was observed as patients and carers in particular felt that in the force of the drive to discharge their context and best interests were not at the heart of discharge decision making.

A loss of trust was also observed between hospital and community health professionals, with community professionals feeling the drive to discharge, rather than patient need, was the priority. Community health professionals perceived the response of hospital health professionals to the drive to discharge was to keep throwing bags on the 'conveyor' regardless of circumstances. However, this was not the case as health professionals were not comfortable with the speed of discharge and they were aware of the dehumanising aspect of the conveyor belt and the lack of choice and control. Therapists were still trying to carry out rehabilitation, even though patient admission times were decreasing to the point where they were able to do little more than assess and move on to the next new admission. The drive to discharge had changed the nature and purpose of the community hospital and this had not been communicated to hospital or community health professionals. The lack of communication was exacerbating the gap between hospital and community, with services taking several weeks to commence. Whilst the drive to discharge is prompted by a lack of resources it also causes demands on resources that are not being met. The lack of availability of resources to cater to the needs of patients and carers results in power in the drive to discharge process and a lack of ability for health professionals to enable genuine choice, which ultimately is a dissatisfying experience for everyone. Poor or unfair outcomes are a result of not embracing the complexity of the patient/carer intersection in a bureaucratic system that prioritises assessment, documentation and check lists; 'poor communication is to be expected as the systems within which practitioners work predispose towards this' (Procter et al, 2001, p.216). Health professionals are therefore unable to take into account complex circumstances due to the domination of healthcare by 'technical rationality' (Proctor et al, 2001). The literature has shown how relationality is key to conceptualising the patient and their context and to improving care.

As Collins and Blige (2016) said, 'Intersectionality is a tool we can all use in moving toward a more just future.' Embracing complexity can be achieved by using the core ideas of relationality, social context, power, inequality and social justice to highlight and explore

intersections. Intersectionality has enabled us to look at the thread connecting across domains, such as structural and societal issues, for example, neoliberalism, biomedicalisation of age and dying and ageism, as well as interpersonal interactions between health professionals themselves, with the patients and with the carers, and how power can vary in these interactions but that the power of the drive to discharge remains constant and unchanged. Corus and Saatcioglu (2015) advocate the use of intersectionality to create services that include patients and carers in order to incorporate 'awareness and tolerance of the diversity of patient and public aspirations for, and responses to, the intrinsically difficult and distressing experience of death and dying' (p.329). However, in a setting where 'staff have insufficient opportunity or time to gather in-depth knowledge regarding the needs and vulnerabilities faced by consumers, manifestations of discriminatory and disrespectful encounters can occur' (Corus, 2015, p.419). This fuels the mismatches in expectations between stakeholders seen in the findings and means that health professionals will avoid finding out more about potential issues that may occur after discharge, or regarding the carer's capacity to care.

The table below uses the Collins and Blige (2016) core ideas of the intersectional framework to summarise the key points of the study, plus the implications from an ethical perspective.

Intersectionality framework	Key points of reference to this study	Ethical perspective implications
Social inequality. Using intersectionality as an analytic tool encourages us to move beyond seeing social inequality through race-only or class-only lenses. Instead, intersectionality encourages understanding of social inequality based on interactions among various categories.	Helps us to view people as not just 'old' or 'frail'. Older people are subject to ageism, as well as the medicalisation of frailty, age and death. Also, the societal perceptions of deterioration and no longer useful to society disadvantage older people. Furthermore, from a life course perspective, other determinants of health would have intersected to produce an individual's current health/wellbeing.	Fairness and justice – equal distribution of palliative care to older people and younger people. Ageism. Assumptions about female caring role as natural and expected. Greater burden placed of females. Gender norms.

Intersectionality framework	Key points of reference to this study	Ethical perspective implications
Power. Intersectional frameworks understand power relations through a lens of mutual construction. In other words, people's lives and identities are generally shaped by many factors in diverse and mutually influencing ways. Moreover, race, class, gender, sexuality, age, disability, ethnicity, nation and religion, among others, constitute interlocking, mutually constructing or intersecting systems of power. Within intersectional frameworks, there is no pure racism or sexism. Rather, power relations of racism and sexism gain meaning in relation to one another. Furthermore, power relations are to be analysed both via their intersections, as well as across domains of power, namely structural, disciplinary, cultural and interpersonal.	Power is found all the way through the analysis in the healthcare system/drive to discharge, policy, an ageist society and so on, as well as within individual interactions between health professionals and patient/carer and between patient and their carer. Where there is power and prejudice (as seen in social inequality) in combination, discrimination can be found. Therefore it is important to scrutinise the power element to see where discrimination happens and why.	Ensuring no harm to patient or carer from system priority of achieving discharge. Relational ethics/moral distress to cope with drive to discharge constraints/power – healthcare professionals (HCP) understand own power and view patient and carer in interrelated way. Ensuring no harm re assumptions of caring role and ability of carer to carry out role – appreciate the power of the patient over the carer by prioritising patient autonomy. Viewing patient through relational autonomy lens. Empowerment of carer through adequate information and early involvement. Power of the drive to discharge to influence professional practice and modify community hospital purpose.

Intersectionality framework	Key points of reference to this study	Ethical perspective implications
Relationality. Relational thinking rejects 'either/or' binary thinking, instead embracing 'both/and', thus shifting from differences between race and gender to interconnection. Power is better conceptualised as a relationship, as in power relations, than as a static entity. Power constitutes a relationship rather than a thing to be gained or lost.	Relationality and Social context are inextricably linked. As mentioned above, there is power in the relationships, i.e. older person and their carer, older person and the drive to discharge, carer and drive to discharge, as well as the patient/carer dyad and the drive to discharge. Intersectionality enables us to view the drive to discharge in a relational way in order to uncover the nature of its power.	Relational autonomy. Patient is an autonomous individual within a complex and interdependent social network. Relationality of old age and dying. Relational ethics to guide practice.
Social context. The term 'contextualise' comes from the impetus to think about social inequality, relationality and power relations in a social context. Attending to social context grounds intersectional analysis.	The social, political, historical and intellectual context of each element of the Venn grounds the study. In this study the context where the relationship between older person and carer intersects sheds light on how power is wielded within relationships in the context of the drive to discharge, and how that can give rise to discrimination/differential outcomes. Intersectionality enables us to look at the rhetoric of 'choice' and how it is complex, relational and subtly negotiated and shaped by social context.	Context of the older person (inc. ageism, etc.) and their carer (inc. assumptions made by patient and HCP re caring role). Carer's own context. Wider situation at hospital as well as at policy level.

Intersectionality framework	Key points of reference to this study	Ethical perspective implications
Complexity. The core themes of social inequality, power, relationality and social context are intertwined, introducing an element of complexity into intersectional analysis. Intersectionality itself is a way of understanding an analysing the complexity of the world.	Complexity is an important tool in the analysis as health and social care systems are not merely complicated but complex, and require more than a linear analysis. For example, the patient's health, social and environmental issues are complex in themselves. When intersecting with the carer's own health, social and environmental issues (which are not such a high priority) further complexity is created. Older people and their carers are not homogenous, and intersectionality provides a form of analysis that helps to understand the complexity.	Complexity of patient and carer dyad. Ethical consideration of carer circumstances. SW/doula role to relieve admin burden, navigate systems and mobilise compassionate communities. Integration of geriatrics and palliative care to reduce system complexity and improve equality of care. The HUB – multidisciplinary working/reduce silo working.
Social justice. Fairness is elusive in unequal societies where the rules may seem fair, yet are differentially enforced through discriminatory practices. Fairness is also elusive where the rules themselves may appear to be equally applied to everyone yet still produce unequal and unfair outcomes.	Rules of discharge appear to be applied equally, but older people are subject to different definitions of 'choice' compared to younger 'frail' adults. Furthermore, the concept of 'choice' does not seem to apply to their carer. Therefore, exploring the points at which power and bias/prejudice intersect can shed a light on how/where discrimination could arise and be hidden behind a regulatory façade and policy buzzwords.	Carer consent. Informed consent – fully made aware of the burdens and wishes respected. Limitations of the system not used to force people to take on more than they can cope with. Choice and control for patient *and* carer. Benefits to patient when carer is more emotionally available after burden is lessened (Broom, 2013).

Table 7: Intersectional framework with key points relating to this study

In the next chapter the study conclusion and recommendations are presented. A personal reflection regarding the research process and findings will also be included.

Chapter 6: Conclusion and Recommendations

6.1: Conclusion

This chapter will start by reviewing the study findings in relation to the research questions. This is followed by a discussion regarding study limitations, the implications for practice and education, and suggestions for future research.

6.2: The research questions

In this constructivist, grounded theory study a substantive theory was developed from the empirical data, which was obtained from the analysis and interpretation of the interviews. These had been undertaken with stakeholders involved in the discharge of an older person living with frailty who were approaching the end of life, and included the patient, their informal carer(s), community hospital and community health professionals, and care home managers. The research questions were:

- How is discharge perceived and understood by stakeholders?
- How is discharge experienced by stakeholders?
- What structures and processes are in place to facilitate discharge?

Perceptions and experiences of the stakeholders were varied but unified by 'the drive to discharge conveyor belt' and the processes that cause and perpetuate it. Structures and processes that facilitate discharge power the drive to discharge by homogenising patients, blurring the complexity of a patients' context and making assumptions about how people live and the caring role, as well as deciding what services will commence after discharge. The concept of choice was often used as a justification for the drive to discharge, but the reality of choice was often limited for the patient and their carer or not taken into consideration at all. It has been discussed how older people living with frailty are a disadvantaged group and their carers are further disadvantaged, particularly when overwhelmed by the power of the drive to discharge and set adrift by lack of resources in the community. Choices made by patients are based on many different factors that the drive to discharge may not allow for or anticipate. People will not always behave as policy anticipates, for example rehabilitating better in a ward environment than at home. People may not have the social network or confidence that policy expects; therefore, home is not always best. The drive to discharge, resource limitations, mismatches in expectations and patient choice all cause a burden to

the carer, which is exacerbated by a focus on patient-centeredness rather than the patient/carer intersection. The carer needs to be taken into account as they are 'intrinsic' to the discharge process and to ensuring that the patient remains in their place of choice post-discharge. The carer is a valuable resource that is not inexhaustible. They are also a future NHS user and the drive to discharge risks becoming a loop that creates more patients. Caring for an older person living with frailty is hard work and stressful. When there is no informal carer the patient is reliant on community services and care homes whose agenda may not match with the patient's. Physiotherapy prior to discharge and the occupational therapy home assessment were found to be key to facilitating a good discharge, but these have been limited by the pressure to discharge. Therapists felt unable to carry out adequate care and nurses were concerned they were not doing a good job. The drive to discharge therefore created a dynamic whereby health professionals were both empowered to push the discharge forward whilst disempowered to work as per their professional standards.

Intersectionality has given a unique perspective of the structures and processes in place to facilitate discharge and how they add power to the drive to discharge and disempower older people and their carers. There is a complexity inherent in frailty, end of life, discharge and family dynamics. Intersectionality has illuminated the importance of the older person/carer intersection and inequality and injustice experienced by both older people and, even more so, their female carers, which the systems needs to acknowledge and accommodate in order to improve the experiences of older people and their carers. Using an ethical framework helps to apply the intersectional insights to practice.

6.3: Strengths and limitations of the study

The key strengths and limitations of the study are outlined in the following section.

6.3.1: Strengths of the study

A key strength of the study is that it extends knowledge, addresses a gap in the literature and provides new insight into the experiences of stakeholders involved in the discharge from community hospital of an older person living with frailty who is approaching the end of life. The substantive theory has been articulated as the drive to discharge conveyor belt and furthers the understanding of the experience of discharge from hospital for older people living with frailty at the end of life, and those who care for them both formally and informally. It illuminates the complexity of a system under pressure that prioritises the discharge over everything else. Intersectionality has also illuminated the complexity of

working within the system, as well as being a patient and carer subjected to the system. It provides a potential framework for future research and may provide a useful approach to the development of discharge processes that acknowledge the importance of the carer for a successful discharge and the need to support them whilst embracing the complexity of the patient/carer intersection in order to improve outcomes and experiences and reduce inequalities by providing more real choice and control to patients and carers.

6.3.2: Limitations of the study

Several potential limitations were identified which related to the methodological considerations of the study. In order to make these limitations transparent and open to critique, these are now discussed.

The sample was all white British and from one community trust. However, participants were recruited via four different community hospitals around the county. Whilst participants were representative of the population in this geographical area, it is not necessarily representative of the UK population as a whole. Therefore, these findings are not generalisable to the general population or different cultural or religious settings, but they do deepen the knowledge regarding discharge of older people living with frailty at the end of life.

Not including older people with dementia excluded a large portion of the aged population, but dementia studies require specific attention and criteria. The study is not representative of all older people; indeed those with dementia may have worse experiences as they are further disadvantaged by their mental health status and the stigma attached to it.

Whilst the study sought the views of stakeholders, it was difficult to contact all of them, particularly community nurses, and consequently there were no community nurses involved in the study. The community nurses operate a central phone number manned by administrators. It is not possible to speak directly to a nurse or manager. I attempted contact but I am sure this was easily ignored in a very busy team with a high case load. As a result, community nurses are not represented in this study, and it must be acknowledged that they are an important profession when patients are discharged to the community, particularly for older people living with frailty who are at the end of life.

Another limitation of the study is that interview data was collected at only one point in time, which was shortly after the discharge. However, the impact of the discharge process could be felt for some time after the event and a longitudinal approach would have enabled a

deeper understanding of what happens after the discharge, what caused readmissions and how the carer burden may change over time.

6.4: Recommendations from the study findings

A number of recommendations are proposed from the findings of the study. These recommendations relate to the clinical practice, education and further research in the areas of older people, frailty, end of life and hospital discharge. Intersectionality emphasises the need for health programmes to be informed by intersectionality and to 'offer an environment in which healthcare professionals can have the opportunity to gain nuanced knowledge about the lived experience of those at the convergence of multiple stigmatizing identities', but may slow the discharge down (Corus & Saatcioglu, 2015, p.426). Recommendations relate to the discharge/patient/carer intersection and how the drive to discharge could acknowledge and incorporate the complexity inherent in the older person/carer intersection in order to decrease injustice and inequity created by the drive to discharge.

6.4.1: Recommendations for clinical practice

The HUB was identified as a good multidisciplinary group that reduced silo working and improved information sharing. Improved communication through referral letters would increase transparency and trust whilst reducing silo working. Including older people and their carer would increase the opportunity for choice to be expressed and avoid assuming family members, especially daughters can care without psychological and physical impact. If the older person or their carer cannot be present, someone with a focus that is not biomedical/discharge facilitation/admission avoidance, such as social worker, could represent the older person and their carer and promote/facilitate a compassionate communities approach. A cost-benefit analysis of the use of social workers would be a first step.

The patient/carer intersection and the importance of the carer needs to be embraced and not avoided for fear of complexity slowing down the drive to discharge. Applying an ethical framework to carers could enable them to be more fully informed, as well as having their wishes respected, so that the concept of informed decision making and consent can be applied to carers and obtained. The carers themselves also require support and may need community resources mobilised to support them as well as a single point of coordination to refer to as the patient's condition changes. An environment where care takes place without

coercion requires an understanding of the carer's context and for health professionals to not be judgemental if a carer says they cannot cope. The carer also needs to be educated as to what exactly will be required of them after discharge so that they can make an informed decision. In the study many carers did not realise just how much work they would be carrying out in order to support the older person. Again, social workers are the ideal profession to help navigate systems and mobilise support.

Occupational therapy and physiotherapy prior to discharge are important, as was a smooth transition to community rehabilitation, in order to reduce the deterioration of the patient whilst waiting for continuation of therapy, but also to support the carer who is filling the gap. Occupational therapy home assessments were found to be especially helpful as they embrace the complexity of the patient's context, which helps to prevent problems from arising that may jeopardise success of the discharge.

Clearer communication regarding the role and purpose of a community hospital would make it plainer what hospital staff are supposed to be achieving and clarify to community health professionals what is needed after discharge. If it were clearer that older people with frailty were not going to be rehabilitated to the extent that they used to be, perhaps a frailty pathway could be created that indicates that the intermediate care team need to collect patient off the conveyor belt immediately after discharge. Communication via the computer system or letters was found to be important in the transfer of information. A 'frailty pathway' would support this.

The literature supports an integration of palliative care and geriatrics to ensure that the end of life needs of older people living with frailty are met as frailty is an end of life stage. This study found that only those older people with cancer were referred to the hospice in spite of all patients being identified as having approximately six months to live. An integration of palliative care and geriatrics would mean that referral to specialist services is not necessary. Integrated care has been shown to improve outcomes for older people living with frailty, as per Torbay Care Trust (Section 5.8), including reduced use of hospital beds, low rates of emergency admission and minimal delayed transfers of care between services.

6.4.2: Recommendations for education

Open discussion about ageism, gender norms and assumptions about the caring role is required so that future clinicians can be conscious of the conflict between the patient in policy and the patient in the bed. The care of older people living with frailty as an end of life

condition would open the way to a more integrated way of conceptualising older people as they 'dwindle'. Education regarding the importance of the patient/carer intersection and social network for older people with frailty living in the community is important as it is unlike any other intersections, and the options open to these disadvantaged groups are not the same as other patient groups. Viewing death as relational and as a part of life will enable people to view the older person/carer intersection in a more holistic way and not to shy away from the complexity inherent in the situation and the needs of the older person and their carer. Applying an ethical framework that takes into account the carer's autonomy and consent, not just the patient's, is important to reduce injustice and burden or harms. Discussion is also required around juggling the demands of the system verses professional ethics and standards of care and how the discrepancy can result in moral distress.

6.4.3: Recommendations for policy

The concept of integrated care has been promoted for a long time, with a genuinely seamless service from hospital to community. This would reduce the 'cracks' that people fall through and that carers make a lot of effort to bridge, which causes them harm. However, moves to genuine integration are slow. A restructuring of palliative care to accommodate older people living with frailty who are approaching the end of life might be hard to achieve financially but also because these services are reliant on prediction of death. Services that allow for 'dwindling' come in the form of enhanced services that can cope with the future increased demand, such as generalist rehabilitation teams being trained to give a palliative approach and foster compassionate communities, while also providing rehabilitation to maximise independence – for example, the intermediate care team who work in the community. The literature supports an integration of palliative care and geriatrics that needs to be incorporated into policy rather than focusing solely on successful ageing aspects of frailty; the HUB does do this, but as mentioned above it has no representation for the older person or carer voice. The emphasis on shifting patient care to the community requires the resources to shift with the patient in order to maintain patient-centeredness, and to support the carer adequately.

At a Trust level, there appears to be a lack of communication to staff and the community trust regarding the vision for what the community hospital goals and priorities are, which causes a loss of trust between services and staff and also fosters silo working. There also appears to be a lack of communication of how the community hospital envisions what services the patients will receive once discharged, and how soon these services will start

post-discharge. A defined pathway, as suggested by a couple of participants, would be beneficial here.

Whilst the policy focus on patient choice is a noble one, it is often a double bind in the guise of choice. A commitment to offering genuine choice would promote more equitable outcomes. Furthermore, the choice of the carer also needs to be taken into consideration. An ethical framework whereby the carer is given the benefit of informed consent processes would reduce the risk of harm from the carer burden. Informed consent would enable the carer to express their choice also.

6.4.4: Recommendations for further research

This study has added to the growing body of research that has explored frailty, end of life and discharge and included a range of stakeholders. The study has provided a foundation for future research, which could encompass the following considerations:

- The current study sample consisted of white British people, which is not representative of all older people living with frailty across the United Kingdom. Further research exploring wider ethnic and socio-demographic populations of patients would enable a greater understanding of the phenomenon.
- Further research on frailty, end of life, hospital discharge, looking at intersections more to improve services, outcomes and experiences of staff, not just older people and their carers.
- Longitudinal design to examine the continuing impact on patient and carer of the discharge. This could include reasons for and consequences of readmissions: What prevented them or caused them? What was going on in the intersection? How has the burden on the carer changed? What changed it? How did their experiences change?
- The effect of the drive to discharge on other patient populations and their informal and formal carers. What can help the people on the conveyor belt and the carers who catch them when they topple off, as well as the health care professionals who gather them up after discharge?
- Discharge has to happen, and the study showed it is never really that successful from the perspective of all stakeholders. Mapping where people go and where the burden lies could enable researchers to see what could lessen the burden/improve the discharge,

how to reduce the cracks between services, and how to improve outcomes for older people and their informal carers.

- The older people in my study did not want to go to a care home but had no choice unless there was an informal carer who could take on the burden. If choice is truly to be extended to older people, the options need to be mapped, with the barriers to community support/living clearly identified so that a solution can be found.

- A carer's assessment already exists, but some people are not identified by themselves or by healthcare professionals as being carers and are not receiving the assessment. Furthermore ,the carer's assessment tends to be used with the spouses of older people, not their children. Perhaps an ethical framework and/or intersectional principles could be applied to older people and their carers to better capture who needs help and how to help them. There also needs to be some sort of feedback mechanism whereby carers are enabled to voice their dissatisfaction with the discharge.

- This study found some carers more knowledgeable than others due to previous experiences of health and social care and due to a kind of resilience. What made them more able to cope with the burden of caring for an older person living with frailty? Can they help others? Does a carer knowledge sharing platform exist and is it used? What carer support is out there? Can carers support each other? A carer typology could find out which strengths enable some carers to cope, in order to inform researchers how those that are not coping as well can be helped to bear their burden.

- An exploration is needed of how palliative care can be implemented in generalist settings to benefit older people at the end of life, exploring aspects of palliative care such as goal setting, management of expectations and reducing acute care utilisation.

- Are/should commissioners be involved in the concept of the 'frailty pathway' in order to reduce gaps in care and to integrate palliative care and geriatrics? This would include looking at current resources as well as the costs of any implications for policy change and/or service reconfiguration.

6.5: A personal reflection on the doctoral process

Section 1.2 provided a reflection regarding the research rationale and the importance of reflexivity in constructivist grounded theory. Furthermore, in Section 3.7.2.1 I reflected on the differences and similarities between therapeutic and research interviews and how my

profession influenced data collection. As an occupational therapist I was heartened by the hard work of health professionals but dismayed to hear how poorly community therapists thought of hospital therapists, and how this often results in a lack of trust. This study helped me to see how the drive to discharge influences these thoughts as well as practice. It reminded me of working in the community and being critical of the work hospital therapists were doing, and the feeling that they were just passing the buck in order to achieve a quick discharge. When I return to practice I will have a new perspective on silos and how they are formed and perpetuated and will be more sympathetic to those who are feeling the disempowering push of the drive to discharge the most.

The study has helped me to understand the whole system more effectively and I now have an overview of how health professionals work within the push of a system under duress, and how this influences intersections within the system with the patient and their carer. Furthermore, it has developed how I conceptualise patient treatment, but also how the patient treats their carer, as well as how health professionals treat the carer too. I now have far more understanding of the biases within society and policy that leave carers feeling that they have no choice and no support in the role. When I return to practice, I will be paying more attention to the role of the carer and their intersection with the patient or service user.

Although I set out to interview patients that were being discharged from acute hospitals and who were to receive palliative care in the community, recruitment problems meant that I moved to community hospitals. This meant that the patients were older people living with frailty. As frailty can be argued to be an end of life stage I felt this was relevant and a literature review showed that little is known about this specific group at the end of life, when they are discharged from hospital. The grounded theory methodology enabled me to highlight a gap in knowledge and for the issue regarding the carers' role to come to the fore. The situational maps enabled me to capture the complexity of the situation and to analyse it.

I loved interviewing people in their homes and it reminded me very much of my community work. Participants were interviewed in their own home (or care home) for their convenience and to benefit the power dynamic. They were very generous with their time and thoughts. I particularly appreciated how candid carers were when describing their frustration, despair and upset. It cannot have been easy, but I hope they felt better for someone listening to their worries. Where possible, I provided signposting to further ensure that no one was left feeling unsupported.

The doctoral process has also developed my skills to manage a large project and to carry out literature reviews effectively. The method for data analysis using messy maps, as well as coding, felt creative and intuitive and grounded the data in the participants' voices.

6.7: Chapter summary

The recommendations drawn from my study are grounded in participant voices, with some suggested directly by participants. Whilst some recommendations may be rejected as unrealistic, they are also supported by the literature and the study findings. Intersectionality of core concepts and an ethical framework can help to conceptualise patients and their family, free of ageism and gendered assumptions in order to inform practice, education, policy and research and to improve outcomes and justice.

References

Abel, J. & Kellehear, A. (2016). Palliative care reimagined: a needed shift. *BMJ Supportive & Palliative Care,* 6, 21–26.

Acott, K. & Searby, S. (2012). Informed consent: adults and capacity. In Gallagher, A. & Hodge, S. (Eds.) *Ethics, law and professional issues. A practice-based approach for health professionals*. London: Palgrave Macmillan.

Adam, J. (2000). Discharge planning of terminally ill patients home from an acute hospital. *International Journal of Palliative Nursing*, 6(7), 338–345.

Agar, M., Currow, D., Shelby-James, T., Plummer, J. & Sanderson, C. (2008). Preference for place of care and place of death in palliative care: are these different questions? *Palliative Medicine* 22(7), 787–795.

Age UK (2016). *End of life policy position paper*. London: Age UK.

Allen, G. (2003). A critique of using grounded theory as a research method. *Electronic Journal of Business Research Methods,* 2.

Andrews (2012) What is Social Constructionism? *Grounded Theory Review. An International Journal.* Available online at: groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/ [Accessed 10.09.18].

Andrews, T. (2015). Awareness of dying remains relevant after fifty years. *Grounded Theory Review. An international journal.* Available online at: http://groundedtheoryreview.com/2015/12/19/awareness-of-dying-remains-relevant-after-fifty-years/ [Accessed 04.02.21].

Back, A.L., Young, J.P., McCown, E., Engelberg, R., Vig, E., Reinke, L., Wenrich, M., McGrath, B. & Randall Curtis, J. (2009). Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: Loss of continuity and lack of closure. *Arch Intern Med.* 2009, 169(5), 474–479.

Baillie, L., Gallini, A., Corser, R., Elworthy, G., Scotcher, A. & Barrand, A. (2014). Care transitions for frail, older people from acute hospital wards within an integrated healthcare system in England: a qualitative case study. *International journal of integrated care,* 14, 1–11.

Bateson, G., Jackson, D.D., Haley, J., & Weakland, J. (1972). *Double bind. Steps to an ecology of mind.* London: University of Chicago Press

Bauer, M., Fitzgerald, L., Haesler, E. & Manfrin, M. (2009). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing,* 18, 2539–2546.

Beauchamp, T. & Childress, J. (2009) *Principles of Biomedical Ethics*. United Kingdom: Oxford University Press.

Benzar, E., Hansen, L., Kneitel, A. & Fromme, E. (2011). Discharge planning for palliative care patients: A qualitative analysis. *Journal of palliative medicine,* 14(1), 65–69.

Berger, P. & Luckmann, T. (1966). *The Social Construction of Reality. A Treatise in the Sociology of Knowledge*. Middlesex: Penguin.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice Hall.

Bone, A., Morgan, M., Maddocks, M., Sleeman, K., Wright, J., Taherzadeh, S., Ellis-Smith, C., Higginson, I. & Evans, C. (2016). Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders, *Age and Ageing*, 45(6), 863–873.

Borgstrom, E. (2015). Planning for an (un)certain future: choice within English end of life care. *Current Sociology Monograph,* 6(5), 700–713.

Borgstrom, E. (2016a). National end of life care policy in the English context: The problem and solution to death and dying. In Woodthorpe, K. & Foster, L., (Eds.) *Death and social policy in challenging times*. 35–52. London: Palgrave Macmillan.

Borgstrom, E. (2016b). Social Death. *QJM: An International Journal of Medicine*, 110(1).

Braun, V. & Clarke, V. (2013). *Successful Qualitative Research. A Practical Guide for Beginners*. London: Sage.

Breckenridge, J., Jones, D., Elliott, I. & Nicol, M. (2012). Choosing a Methodological Path: Reflections on the Constructivist Turn. *Grounded Theory Review*. http://groundedtheoryreview.com/2012/06/01/choosing-a-methodological-path-reflections-on-the-constructivist-turn/ [Accessed: 13.07.17].

Brinkmann, S. & Kvale, S. (2015). *InterViews. Learning the craft of qualitative research interviewing*. Third edn. London: Sage.

British Geriatric Society (BGS) (2020). End of Life Care in Frailty: Identification and prognostication. Available online: https://www.bgs.org.uk/resources/end-of-life-care-in-frailty-identification-and-prognostication [Accessed 15.04.21].

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 513–531.

Broom, A. & Kirby, E. (2013). The end of life and the family: hospice patients' views on dying as relational. *Sociology of Health of Heath and Illness*, 35(4), 499–513.

Bunt, S., Steverink, N., Olthof, J., van der Schans, C. P., & Hobbelen, J. (2017). Social frailty in older adults: a scoping review. *European journal of ageing*, 14(3).

Burr, V. (2003). *Social constructionism*. Second edn. London: Routledge.

Calasanti, T. & Slevin, K. (2006). *Age Matters: Realigning Feminist Thinking*. London: Routledge.

Calasanti, T. & Giles, S. (2018). *The challenge of intersectionality. American society on ageing.* Available online at: https://www.jstor.org/stable/10.2307/26556320 [Accessed 03.02.21].

Camp, M., Jeon-Slaughter, H., Johnson, A. & Sadler, J. (2018) Medical student reflections on geriatrics: Moral distress, empathy, ethics and end of life. *Gerontology & Geriatrics Education*, 39:2, 235–248.

Care Quality Commission (CQC) (2016). A different ending. Addressing inequalities in end of life care. Available online at: https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf [Accessed 10.09.18]

Catt, S., Blanchard, M., Addington-Hall, J., Zis, M. & Blizard, R. (2005). Older adults' attitudes to death, palliative treatment and hospice care. *Palliative Medicine,* 19(5), 402–410.

Charmaz, K. (1995). Grounded theory. In Smith, J. A., Harre, R. & Van Langenhove, L. (Eds.), *Rethinking methods in psychology*, 27–49. London: Sage.

Charmaz, K. (2002). Grounded theory analysis. In Gubrium, J.F. & Holstein, J.A. (Eds.), *Handbook of interviewing research,* 675–694. Thousand Oaks, CA: Sage.

Charmaz, K. (2014). *Constructing Grounded Theory*. Second edition. London: Sage.

Charmaz, K. (2017). The power of constructivist grounded theory for critical inquiry. *Qualitative inquiry*, *23*(1), 34–45.

Chiovitti, R.F. & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing,* 44(4), 427–435.

Clark, D. (2014). *Cicely Saunders, the 1960s and the USA*. Available online at: http://www.ehospice.com/ArticleView/tabid/10686/ArticleId/11571/View.aspx [Accessed 11.07.17].

Clarke, A. (2005) *Situational Analysis—Grounded Theory After the Postmodern Turn*. Thousand Oaks, CA: Sage.

Clarke, A., Friese, C. & Washburn, R. (2015). *Situational analysis in practice. Mapping research with grounded theory*. Abingdon: Routledge.

Colich, N., Rosen, M., Williams, E. & McLaughlin, K. (2020). Biological Aging in Childhood and Adolescence Following Experiences of Threat and Deprivation: A Systematic Review and Meta-Analysis. *Psychological Bulletin*, 1–44.

Collins, P. & Blige, S. (2016). *Intersectionality*. Cambridge: Polity Press.

Community hospitals association (2016). *A selection of definitions and descriptions of community hospitals*. Available online at: http://www.communityhospitals.org.uk/pdf/CHA/CHA_Definitions_CH2016.pdf [Accessed 03.02.21].

Coombs, M., Long-Sutehall, T., Darlington, A. & Richardson, A. (2015). Doctors' and nurses' views and experience of transferring patients from critical care home to die: A qualitative exploratory study. *Palliative Medicine,* 29(4), 354–362.

Corbin, J. & Strauss, A. (2014). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory*. London: Sage.

Corus, C. & Saatcioglu, B. (2015). An intersectionality framework for transformative services research. *The services industries journal,* 35(7–8), 415–429.

Costa, A.L. & Kallick, B. (1993). Through the lens of a critical friend. *Educational leadership*, 51, 49–49.

Covinksy, K., Eng, C., Lui, L., Sands, L., Yaffe, K. (2003). The Last 2 Years of Life: Functional Trajectories of Frail Older People. *Journal of the American geriatric society*. 51(4), 492-498.

Cruickshank, J. (2012). Positioning positivism, critical realism and social constructionism in the health sciences: a philosophical orientation. *Nursing Inquiry*, 19(1), 71–82.

Danziger, K. (1997). The Varieties of Social Construction. *Theory & Psychology,* 7(3), 399–416.

Davidson, D., Paine, A., Glasby, J., Williams, I., Tucker, H., Crilly, T., Crilly, J., Le Mesurier, N., Mohan, J., Kamerade, D., Seamark, D. & Marriot, J. (2019) *Analysis of the profile, characteristics, patient experience and community value of community hospitals: a multimethod study.* London: HMSO.

Department of Health (2005). *Mental Capacity Act*. London: HMSO.

Department of Health (2008). *End of Life Care Strategy*. Available online at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf.

Department of Health (2013). *The Care Bill*. London: HMSO.

Department of Health (2014). *Five Year Forward View*. London: HMSO.

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: HMSO.

Department of Health (2017). *One year on. The Government Response to the Review of Choice in End of Life Care*. London: HMSO.

Department of Health (2019). NHS Long Term Plan. Available online at: https://www.longtermplan.nhs.uk/. [Accessed 14.07.21].

Department of Health, Social Services and Public Safety (2010). *Living Matters, Dying Matters Strategy: A Palliative and End of Life Care Strategy for Adults in Northern Ireland.* Department of Health, Social Services and Public Safety: Belfast. Available online at: www.dhsspsni.gov.uk/8555_palliative_final.pdf. [Accessed 11.7.17]

Deschenes, S. & Kunyk, D. (2020). Situating moral distress within relational ethics. *Nursing Ethics*. 27(3), 767–777.

Dixon, J., King, D., Matosevic, T., Clark, M., Knapp, M. & Fellow, R. (2015). *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London: PSSRU.

Dopson, S. (2009). Changing forms of managerialism in the NHS. In Gabe, J. & Clanan, M. (Eds.) *The new sociology of the health service,* 37–55. Abingdon: Routledge.

Drought, T. & Koenig, B. (2002). 'Choice' in end of life care. *The Gerontologist*, 42(3), 114–128.

Ekdahl, A., Linderholm, M., Hellström, I., Andersson, L. & Friedrichsen, M. (2012). Are decisions about discharge of elderly hospital patients mainly about freeing blocked beds? A qualitative observational study. *BMJ open,* 2(6) p1-8

El-Jawahri, A., Greer, J.A. & Temel, J.S. (2011). Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. *Journal of Supportive Oncology*, 9(3), 87–94.

Ellis, J., Winslow, M. & Noble, B. (2016). Social policy and care of older people at the end of life. In Woodthorpe, K. & Foster, L. (Eds.) *Death and social policy in challenging times*, 17–34. London: Palgrave Macmillan.

End of life care coalition (2017). *The emergency bed crisis: high quality end of life care as a critical part of the solution*. Available online at: http://endoflifecampaign.org/wp-content/uploads/2017/11/End-of-Life-Briefing-2017.pdf [Accessed 31.10.20]

Ewing, G., Austin, L., Jones, D. & Grande, G. (2018). Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) approach. *Palliative Medicine*, 32(5), 939–949.

Fillit, H., Rockwood, R., Young, J. (2002). *Brocklehurst's Textbook of Geriatric Medicine and Gerontology.* Elsevier

Finlay, L. (2006). 'Rigour', 'ethical integrity' or 'artistry'? Reflexively reviewing criteria for evaluating qualitative research. *British Journal of Occupational Therapy*, 69(7), 319–326.

Fisher, A. & Savin-Baden, M. (2002). Modernising fieldwork. *British Journal of Occupational Therapy*, 65(6), 275–282.

Fisher, L. & Lieberman, M. (1999). A longitudinal study of predictors of nursing home placement for patients with dementia. *The Gerontologist*, 39,(6), 677–86.

Fried, L., Tangen, C., Walston, J., Newman, A., Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W., Burke, G., McBurnie, M. (2001). Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology. Series A Biological Sciences and Medical Sciences*, 56(3):M146–56.

Gallagher, A. (2011). Moral distress and moral courage in every day nursing practice. *Online journal of issues in nursing*, 21, 16(2), 8.

Gawande, A. (2015). *Being Mortal*. London: Wellcome Collection.

Gladman, J., Buckell, J., Young, J., Smith, A., Hulme, C., Saggu, S., Godfrey, M., Enderby, P., Teale, E., Longo, R., Gannon, B., Holditch, C., Eardley, H. & Tucker, H. (2016). Understanding the Models of Community Hospital rehabilitation Activity (MoCHA): a mixed-methods study. *BMJ Open* 2017;**7:**e010483. doi: 10.1136/bmjopen-2015-010483.

Glaser, B. (1978). *Theoretical Sensitivity: advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. (1992). *Emergence vs Forcing. Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998). *Doing Grounded Theory*. *Issues and discussions*. Mill Valley, CA: Sociology Press.

Glaser, B. (2001). *The Grounded Theory Perspective: Conceptualisation Contrasted with Description*. Mill Valley, CA: Sociology Press.

Glaser, B. (2005). The Impact of Symbolic Interaction on Grounded Theory. *Grounded Theory Review. An International Journal.* Available online at: http://groundedtheoryreview.com/2005/03/30/1575/ [Accessed 16.08.17].

Glaser, B. & Strauss, A. (1965). *Awareness of Dying.* New Jersey: Traction Publishers.

Glaser, B. & Strauss, A. (1967). *The Discovery of Grounded Theory. Strategies for Qualitative Research.* New Jersey: Traction Publishers.

Glaser, B. & Strauss, A. (1999). *The Discovery of Grounded Theory. Strategies for Qualitative Research*. NY: Routledge.

Gomes, B., Calanzani, N., Koffman, J. & Higginson, I. (2015). Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. *BMC Medicine,* 13, 235.

Goodwin, N. & Smith, J. (n.d.). *The King's Fund and the Nuffield Trust Developing a National Strategy for the Promotion of Integrated Care. The Evidence Base for Integrated Care.* Available online at: https://www.kingsfund.org.uk/sites/default/files/Evidence-base-integrated-care2.pdf [Accessed 06.11.20].

Gott, M., Seymour, J., Bellamy, G., Clark, D. & Ahmedzai, S. (2004). Older people's views about home as place of care at the end of life. *Palliative Medicine*, 18, 460–467.

Gott, M., Small, N., Barnes, S., Payne, S. & Seamark, D. (2008). Older people's views of a good death in heart failure: Implications for palliative care provision. *Social Science and Medicine,* 67, 1113-21.

Gott, M., Ibrahim, A. & Binstock, R. (2011). The disadvantaged dying: ageing, ageism, and palliative care provision for older people in the UK. In Gott, M. & Ingleton, C (Eds.) *Living with ageing and dying. Palliative care for older people*. Oxford: Oxford University Press.

Gott, M., Frey, R., Wiles, J., Rolleston, A., The, R., Moeke-Maxwell, T. & Kerse, N. (2017a). End of life care preferences among people of advanced age: LiLACS NZ. *BMC Palliative Medicine*, 16:76.

Gott, M., Wiles, J., Moeke-Mazwell, T., Black, S., Williams, L., Kerse, N. & Trussardi, G. (2017b). What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers. *Palliative Medicine*, 32(1), 268–275.

Greenhalgh, T. & Papoutsi, C. (2018). Studying complexity in health services research: desperately seeking an overdue paradigm shift. *BMC Medicine,* 16:95.

Groundswell Project (2018). *A 1:1 with Alan Kellehear*. Online video, viewed 24.05.18, https://www.facebook.com/TheGroundSwellProject/videos/2146620968711214/.

Ham, C. & Murray, R. (2015). *Implementing the NHS five year forward view: Aligning policies with the plan.* Available online at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/implementing-the-nhs-five-year-forward-view-kingsfund-feb15.pdf [Accessed 10.09.18].

Hammersley, M. (1992). *What's Wrong with Ethnography*? London: Routledge.

Hankivsky, O. & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health*, 18:3, 271–283.

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(1), 74–83.

Hanratty, B., Lowson, E., Grande, G., Payne, S., Addingtron-Hall, J., Valtorta, N. & Seymour, J. (2014). Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study. *Health Services Delivery Research*, 2(17).

Healthcare Improvement Scotland (2018). *Living well in Communities with Frailty: Evidence for what works.* Improvement Hub.

Heide, A., van Der, de Vogel-Voogt, E., Visser, A., van der Rijt, C. & van der Maas, P. (2007). Dying at home or in an institution: perspectives of Dutch physicians and bereaved relatives. *Supportive Care in Cancer*, 15(12) 1413–1421.

Hestevik, C., Molin, M., Debesay, J., Bergland, A. & Bye, A. (2019). Older persons' experiences of adapting to daily life at home after hospital discharge: a qualitative metasummary. *BMC Health Services Research*. 19:224.

Hirshon, J., Risko, N., Calvello, E., Ramirez, S., Narayan, M., Theodosis, C. & O'Neill, J. (2013). *Health systems and services: the role of acute care*. Available online at: https://www.who.int/bulletin/volumes/91/5/12-112664/en/ [accessed 08.04.20]

Hoare, S., Morris, Z., Kelly, M., Kuhn, I. & Barclay, S. (2015). Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLoS ONE*, 10(11).

Hochschild, A. (2012). *The Managed Heart: Commercialization of Human Feeling*. Oakland, CA: University of California Press.

Holloway, M. (2009). Dying old in the 21st century: A neglected issue for social work. *International Social Work*, *52*(6), 713–725.

Holton, J. A. (2009). Qualitative tussles in undertaking a grounded theory study. *The Grounded Theory Review*, 8, 37–50.

Hospice UK (2017). *Facts and figures about hospice care*. Available online at: https://www.hospiceuk.org/about-hospice-care/media-centre/facts-and-figures [Accessed 10.09.18].

House of Commons Health Committee (2015). *Health Committee: End of Life Care: Fifth Report of Session 2014*–15. London: The Stationery Office Limited. Available online at: www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf [Accessed 10.09.18].

Hughes, Z. & O'Sullivan, L. (2017). Defining and profiling family carers: refelctions from Ireland. *International journal of care and caring,* 1(3), 421–427.

Huijberts, S., Buurman, B. & Rooij, S. (2015). End of life care during and after an acute hospitalisation in older patient with cancer, end-stage organ failure, or frailty: A sub-analysis of a prospective cohort study. *Palliative Medicine*, 30(1), 75–82.

Hutchinson, S. & Wilson, H. (1994). Research and therapeutic interviews: A poststructural perspective, in Morse, J. (Ed). *Critical issues in qualitative research methods*. London: Sage.

Institute for Public Policy Research (2018). End of life care in England. A briefing paper. London: IPPR.

INVOLVE (2017) *What is public involvement in research*? Available online at: http://www.invo.org.uk/ [Accessed 06.07.17].

Jackson, P. & McKergow, M. (2007). The solution focus. Making coaching and change SIMPLE. London: Nicholas Brearley.

Jiwa, M., Coleman, M. & McKinley, R.K. (2005). Measuring the quality of referral letters about patients with upper gastrointestinal symptoms. *Postgraduate Medical Journal*, 81, 467–469.

Johnston, L., Smith, L. & Kowalewski, M. (2014). *How could free social care at end of life work in practice?* London: OPM.

Kaufman, S., Shim, J. & Russ, A. (2004). Revisiting the Biomedicalization of Aging: Clinical Trends and Ethical Challenges, *The Gerontologist*, 44(6), 731–738.

KCC (n.d.) *The Esther Model: Learning from Health and Social Care in Sweden*. Available online at https://www.kent.gov.uk/__data/assets/pdf_file/0011/59069/The-Esther-Model.pdf [Accessed 25.9.20]

Keeble, E., Parker, S., Arora, S., Neuburger, J., Duncan, R., Kingston, A., Hanratty, B., Jagger, C., Robinson, L., Kirkwood, T. (2019a). Frailty, hospital use and mortality in the older population: findings from the Newcastle 85+ study, *Age and Ageing*, 48(6), 797–802.

Keeble, E., Roberts, H., Williams, C., Van Oppen, J. & Conroy, S. (2019b). Outcomes of hospital admissions among frail older people: a 2-year cohort study, *British Journal of General Practice*, 69(685), 555–560.

Kellehear, A (2005). *Compassionate Cities. Public health and end of life care*. London: Routledge.

Kellehear, A (2011). The care of older people at the end of life: a historical perspective. In Gott, M. & Ingleton, C. (Eds.) *Living with ageing and dying. Palliative and end of life care for older people*. Oxford: Oxford University Press.

Kellehear, A (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM*, 106(12), 1071–1075.

Kojima, G., Liljas, A. & Iliffe, S. (2019). Frailty syndrome: implications and challenges for health care policy. *Risk management and healthcare policy*, 12, 23–30.

Larkin, M. & Milne, A. (2017). What do we know about older former carers? Key issues and themes. *Health Soc Care Community*, 25(4), 1396–1403.

Laugaland, K., Aase, K. & Waring, J. (2014). Hospital discharge of the elderly: an observational case study of functions, variability and performance-shaping factors, *BMC Health Services Research*, 14:365.

Leadership Alliance for the Care of Dying People (2014). *One chance to get it right. Improving people's experience of are in the last few days and hours of life*. Available online at: https://www.mendeley.com/viewer/?fileId=5d2c1396-91ee-f3cb-7619-6999fca20cb7&documentId=2e0e4a38-7a76-31eb-b19a-890400376763 [Accessed 10.09.18].

Liberati, A., Altman, D., Tetzlaff, J., Mulrow, C., Gøtzsche, P., Ioannidis, J., Clarke, M., Devereaux, P., Kleijnen, J. & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ* (Clinical research ed.), 339, b2700.

Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Lloyd, L. (2011). What do we know about the congruence between what older people prioritise at the end of life and policy and practices? In Gott, M. & Ingleton, C. (Eds.) *Living with ageing and dying. Palliative and end of life care for older people*. Oxford: Oxford University Press.

Lyonette, C. & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing & Society*, 23(4), 487–506.

Manson, J., Warnock, C. & Crowther, L. (2017). Patient's experiences of being discharged home from hospital following a diagnosis of malignant spinal cord compression. *Support care cancer*, 25, 1829–1836.

Marie Curie (2014). *Living and dying with dementia in England: Barriers to care*. Available online at: www.mariecurie.org.uk/globalassets/media/documents/policy/policypublications/december-2014/dementia-report.pdf [Accessed: 10.09.18].

Marston, C., Agar, M. & Brown T (2015). Patients' and caregivers' perceptions of occupational therapy and adapting to discharge home from an inpatient palliative care setting. *British Journal of Occupational Therapy*, 78(11), 688–696.

Mathar, T. (2008). Making a Mess with Situational Analysis? Review Essay: Adele Clarke (2005). Situational Analysis—Grounded Theory After the Postmodern Turn [37 paragraphs]. *Forum: Qualitative Social Research*, *9*(2), Art. 4. Available online at: http://nbn-resolving.de/urn:nbn:de:0114-fqs080244.

McCann, T. & Clark, A. (2003). A grounded theory study of the role that nurses play in increasing clients' willingness to access community mental health services. *International journal of mental health nursing*. 12(4), 279–287.

MacDonald, M. & Schreiber, R.S. (2001). *Using grounded theory in nursing*, 35–54. New York: Springer Publishing.

MacInnes, J., Baldwin, J. & Billings, J. (2020). The Over 75 Service: Continuity of integrated care for older people in a United Kingdom primary care setting. *International Journal of Integrated Care*, 20. Available online at: https://dx.doi.org/10.5334%2Fijic.5457 [Accessed 06.11.20].

McLennon, S., Habermann, B. & Davis, L. (2010). Deciding to institutionalize: Why do family members cease caregiving at home? *Journal of Neuroscience Nursing*, 42(2), 95–103.

Macmillan (2013). *Time to choose. Making choice at the end of life a reality*. Available online at: https://www.macmillan.org.uk/documents/getinvolved/campaigns/endoflife/timetochoose.pdf [Accessed 10.09.18].

McNamarra, B., & Rosenwax, L. (2010) Which carers of family members at the end of life need more support from health services and why? *Social Science & Medicine*, 70(7), 1035–1041.

Middleton-Green, L., Chatterjee, J., Russell, S. & Downs, M. (2017). *End of life care for people with dementia. A person-centred approach*. London: Jessica Kingsley.

Miller, G. (1997) *Becoming miracle workers. Language and meaning in brief therapy*. New Jersey: Transaction Publishers.

Mills, J., Bonner, A. & Francis, K. (2006). The development of constructivist grounded theory. *International journal of qualitative methods*, *5*(1), 25–35.

Ministry of Health (New Zealand) (2015). *New Zealand Palliative Care Glossary*. Wellington: Ministry of Health. Available online at: http://cdhb.palliativecare.org.nz/new-zealand-palliative-care-glossary-dec15.pdf.

Moback, B., Gerrard, R., Campbell, J., Taylor, L., Minton, O. & Stone, P.C. (2011). Evaluating a fast-track discharge service for patients wishing to die at home. *International Journal of Palliative Nursing*, 17(10), 501–506.

Morgan, T., Williams L.A., Trussardi, G. & Gott, M. (2016). Gender and family caregiving at the end-of-life in the context of old age: A systematic review. *Palliative Medicine*, 30(7), 616–624.

Morse, J. (2010). Sampling in Grounded Theory. In Bryant, A. & Charmaz, K. (Eds.) *The SAGE Handbook of Grounded Theory*, 229–244, London: Sage.

Murray, S., Kendall, M., Boyd, K. & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ*, 330(7498), 1007–1011.

National Council for Palliative Care (2014) *The end of life care strategy: New ambitions*. Available online at: http://www.ncpc.org.uk/sites/default/files/End%20of%20Life%20Care%20Strategy%20New%20Ambitions%20Report_WEB.pdf [Accessed 10.09.18].

National Council for Palliative Care (2016) *Dying well community charter pathfinder project. Evaluation report*. London, NCPC

National End of Life Care Intelligence Network (2012). *What do we know now that we didn't know a year ago? New intelligence on end of life care in England*. Available online at: https://www.basw.co.uk/system/files/resources/basw_54509-1_0.pdf [Accessed: 25.08.20].

National Gold Standards Framework Centre (2011). *The GSF Prognostic Indicator Guidance* (4th edition, October). The Gold Standards Framework Centre in End of Life Care. Available online at: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf [Accessed: 10.09.18].

National Hospice and Palliative Care Association (2016). *History of Hospice Care. A Historical Perspective*. Available online at: https://www.nhpco.org/history-hospice-care [Accessed 09.11.17].

National Institute for Clinical Excellence (2011). *End of life care for adults*. Available online at: www.nice.org.uk/guidance/QS13/chapter/introduction-and-overview [Accessed 10.9.18].

National Institute for Clinical Excellence (2015). *Care for dying adults in the last days of life*. Available online at: https://www.nice.org.uk/guidance/ng31 [Accessed 09.11.17]

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*. Available online at: http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf [Accessed: 10.09.18].

Neuberger, J. (2013) *More care, less pathway. A review of the Liverpool Care Pathway*. Available online at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed 09.11.17].

NHS End of Life Care Programme (2007). *Advance care planning: a guide for health and social care staff*. Available online at: http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf [Accessed 10.09.18].

NHS England (2014). *Actions for End of Life Care: 2014–16*. London: NHS England. Available online at: www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf [Accessed 09.11.17].

NHS Scotland (2008). *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland.* The Scottish Government: Edinburgh. Available online at: www.gov.scot/Publications/2008/10/01091608/0 [Accessed: 09.11.17]

NHS Wales Health Board (2013). Together for Health: Delivering End of Life Care. NHS Wales: Cardiff. Available online at: www.wales.nhs.uk/sitesplus/documents/862/Together_for_Health-Delivering_End_of_Life-Care.pdf [Accessed: 09.11.17].

Office for National Statistics (2017). *Deaths Registered in England and Wales, 2016*. Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths [Accessed 06.08.18].

Oliver, D. (2016). Why is it more difficult than ever for older people to leave hospital? Available online at: https://www.kingsfund.org.uk/blog/2016/05/older-people-leave-hospital [Accessed: 10.4.21].

O'Mara-Eves, A., Brunton, G., McDaid, G. & Oliver, S. (2013). Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. *Public Health Research*, 2013, 1(4).

Pall, L.M. & Manning, L. (2014). Palliative care for frail older people. *Clinical medicine*, 14(3), 292–295. Available online at: https://doi.org/10.7861/clinmedicine.14-3-292.

Park, A., Bryson, C., Clery, E., Curtice, J. & Phillips, M. (Eds.) (2013). *British Social Attitudes: the 30th Report*. London: NatCen Social Research. Available online at: www.bsa-30.natcen.ac.uk [Accessed 10.09.18].

Parliamentary and Health Service Ombudsman (PHSO) (2015). Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. PHSO: London: 2015. Available online at: www.ombudsman.org.uk/reports-and-consultations/reports/health/ dying-without-dignity [Accessed: 10.09.18].

Pelling, M. & Smith, R.M. (1991). *Life, death and the elderly: Historical perspectives*. London: Routledge.

Peters, M., Rand, S. & Fitzpatrick, R. (2019). Enhancing primary care support for informal carers: A scoping study with professional stakeholders. *Health Soc Care Community*. 28(2), 642–650.

Petrova, M., Riley, J., Abel, J. & Barclay, S. (2016). Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. *BMJ Supportive & Palliative Care,* 8, 447–455.

Pickard, S. (2013). Frail bodies: geriatric medicine and the constitution of the fourth age. *Sociology of Health and Illness*, 36: 549–563.

Pinquart, M. & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(1), 33–45.

Pivodic L, Smets T, Gott M, et al. Inclusion of palliative care in health care policy for older people: A directed documentary analysis in 13 of the most rapidly ageing countries worldwide. *Palliative Medicine*. 2021;35(2):369–388.

Pollock, K. (2015). Is home always the best and preferred place of death? *BMJ*, 2015, 351:h4855.

Pollock, K. & Seymour, J. (2018). Reappraising 'the good death' for populations in the age of ageing. *Age and Ageing*, 47, 328–330.

Popejoy, L. (2011). Participation of elder persons, families, and health care teams in hospital discharge destination decisions. *Applied Nursing Research*, 24, 256–262.

Procter, S., Wilcockson, J., Pearson, P. & Allgar, V. (2001). Going home from hospital: the carer/patient dyad, *Journal of Advanced Nursing*, 35(2), 206–217.

Read, T. & Wuest, J. (2007) Daughters Caring for Dying Parents: A Process of Relinquishing. *Qualitative Health Research*, 17(7), 932–944.

Richardson, R. & Kramer, E. (2006). Abduction as the type of inference that characterizes the development of a grounded theory. *Qualitative research*, 6(4), 497–531.

Rockwood, K. (2007). *Clinical Frailty Scale.* Delhousie University. Available online at: https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/rockwood_cfs.pdf [Accessed 22.07.21].

Rogers, J. & Kelly U.A. (2011). Feminist intersectionality: bringing social justice to health disparities research. *Nursing Ethics*, 18(3), 397–407.

Royal College of Occupational Therapy (2015). *Code of conduct.* London: RCOT.

Royal College of Physicians (2017a). *Sustainability and Transformation Plans. What do they mean for physicians?* Available online at: file:///D:/Users/Student/Downloads/RCP%20STP%20summary%20and%20comparison%20(1).pdf [Accessed: 10.09.18].

Royal College of Physicians (2017b). Quality patient care threatened physicians tell PM. Available online at: https://www.rcplondon.ac.uk/news/quality-patient-care-threatened-physicians-tell-pm [Accessed 04.02.21].

Rowe, J. & Kahn, R. (1998). *Successful ageing*. New York: Dell Publishing.

Rubinstein, R. & Medeiros, K. (2015). 'Successful ageing', gerontological theory and neoliberalism: a qualitative critique. *The Gerontologist*, 55(1), 34–42.

Sallnow, L., Richardson, H., Murray, S. & Kellehear, A. (2016) The impact of a new public health approach to end of life care: A systematic review. *Palliative Medicine*, 30(3), 200–211.

Samuel, M. (2020). Covid-19 deaths among social care staff far outstripping those in healthcare. *Community Care*. Available online: https://www.communitycare.co.uk/2020/05/11/covid-19-deaths-among-social-care-staff-far-outstripping-healthcare/ [Accessed: 25.02.21].

Savage, M. (2020). More than half of England's coronavirus-related deaths will be people from care homes. *The Guardian*. Available online at:

https://www.theguardian.com/society/2020/jun/07/more-than-half-of-englands-coronavirus-related-deaths-will-be-people-from-care-homes [Accessed: 01.08.20].

SCIE (2016). Mental Capacity Act 2005 at a glance. Available online at: https://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance [Accessed 06.04.20]

Seale, C., Addington-Hall, J. & McCarthy, M. (1997). Awareness of dying: Prevalence, causes and consequences. *Social Science & Medicine*, 45(3), 477–484.

Seymour, J. (2017). Looking back, looking forward: the evolution of palliative and end-of-life care in England. *Mortality*, 17(1).

Seymour, J., Almack, K. & Kennedy, S. (2010). Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative Care*, 9:4.

Stajduhar, K., Allan, D., Cohen, S. & Heyland, D. (2008). Short Report: Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers. *Palliative Medicine*, 22(1), 85–88.

St Christopher's Hospice (2017*) Dame Cicely Saunders. Her Life and Work*. Available online at: http://www.stchristophers.org.uk/about/damecicelysaunders [Accessed 11.07.17].

Stephenson, J (2018). Campaign to 'end PJ paralysis' saved 710,000 hospital days. *Nursing Times* Available online at: www.nursingtimes.net/news/hospital/campaign-to-end-pj-paralysis-saved-710000-hospital-days-21-08-2018 [Accessed 01.08.20].

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage

Strauss, A. & Corbin, J. (1998). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory.* London: Sage.

Swinkels, J., Tilburg, T., Verbakel, E. & Broese van Groenou, M. (2017). Explaining the gender gap in the caregiving burden of partner caregivers. *The Journal of Gerontology Series B: Phycological Sciences and Social Sciences*, 74(2), 309–317.

Tan, Y. & Blackford, J. (2015). 'Rapid discharge': Issues for hospital-based nurses in discharging cancer patients home to die. *Journal of Clinical Nursing*, 24, 2601–2602.

Tan, Y., Xu, Z., Pang, G., Qu, L., Xu, Y., Zhang, A. & Neo, P. (2016). Facilitating terminal discharge: fulfilling the hospitalised patient's wish for home death in the final hours. *International Journal of Palliative Nursing*, 22(11), 541–548.

Taylor, P. (2020). *The Regressive Power of Labelling People as Vulnerable*. Available online at: https://paulitaylor.com/2020/06/25/the-regressive-power-of-labelling-people-as-vulnerable/ [Accessed 30.06.21].

Teggi, D. (2018). Unexpected death in ill old age: An analysis of disadvantaged dying in the English old population. *Social Science and Medicine*, *217*, 112–120.

Thomas, K. et al (2011). *Prognostic Indicator Guidance (PIG) 4th Edition*. The Gold Standards Framework Centre in End of Life Care CIC.

Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research*, *56*(3), 243–259.

Thornberg, R. & Charmaz, K. (2014). Grounded theory and theoretical coding, in Flick, U. (Ed.) *The SAGE Handbook of Qualitative Data Analysis.* London: Sage.

The Choice in End of Life Care Programme Board (2015). *What's important to me. A Review of Choice in End of Life Care.* The Choice in End of Life Care Programme Board: London. Available online at: www.gov.uk/government/publications/choice-in-end-oflife-care [Accessed 10.09.18].

The Stationery Office (2012a). The Welfare Reform Act. Available online at: http://www.legislation.gov.uk/ukpga/2012/5/contents/enacted [Accessed 10.09.18].

The Stationery Office (2012b). Health and social care act. Available online at: http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf [Accessed 10.09.18].

Truth and Power: an interview with Michel Foucault (1979). *Critique of Anthropology*, 4(13–14), 131–137. Available online at: https://doi.org/10.1177/0308275X7900401311 [Accessed 16.02.21].

Tucker (2016). *Department of Health summary of community hospital definitions*. Available online at: http://www.communityhospitals.org.uk/pdf/CHA/CHA_Definitions_CH2016.pdf [Accessed 10.09.18].

Twigg, J (2004). The body, gender, and age: Feminist insights in social gerontology, *Journal of Aging Studies*, 18(1), 59–73.

Urquhart, C. (2013). *Grounded theory for qualitative research. Practical Guide*. London: Sage.

Vaes, J. & Muratore, M. (2013). Defensive dehumanization in the medical practice: A cross-sectional study from a health care worker's perspective. *British Journal of Social Psychology*, 52, 180–190.

Wang, G., McGrath, B. & Watts, C. (2010). Health care transitions among youth with disabilities or special health care needs: An ecological approach. *Journal of Paediatric Nursing*. 25, 505–550.

Warmoth, L., Lan, I., Phoenix, C., Abraham, C., Andrew, M., Hubbard, R., Tarrant, M. (2016). Thinking you're old and frail: a qualitative study of frailty in older adults. *Ageing and Society,* 36(7): 1483–1500.

Wassel, J. & Cutler, N. (2016). Yet Another Boomer Challenge for Financial Professionals: The 'Senior' Sandwich Generation. *Journal of financial service professionals*, 70, 61–73.

Weiner, C. (2000). *The Elusive Quest. Accountability in Hospitals*. New York: Aldine De Gruyter.

WHO (World Health Organisation) (1998). WHO definition of palliative care. Available online at: www.who.int/cancer/palliative/defnition/en [Accessed 10.09.18].

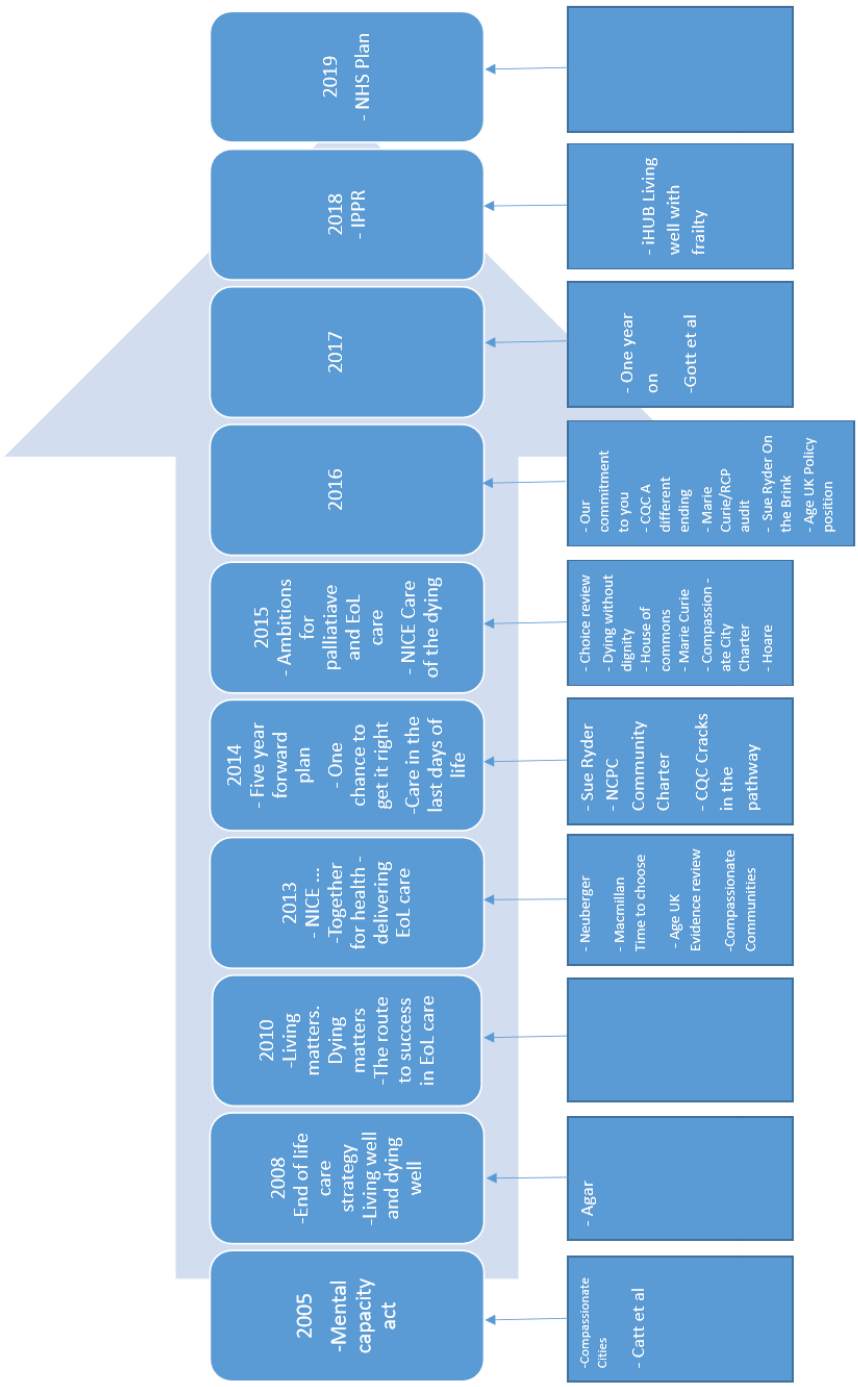
WHO (2017). *WHO Clinical Consortium on Healthy Ageing Topic focus: frailty and intrinsic capacity*. Available online at: https://apps.who.int/iris/bitstream/handle/10665/272437/WHO-FWC-ALC-17.2-eng.pdf [Accessed 08.04.20).

Williams, L.A., Giddings, L.S., Bellamy, G. & Gott, M. (2016). '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(3), 223–230.

Yee, J. & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40(2), 147–164.

Appendices

Appendix 1: Policy summary list for Figure 6



Agar, M., Currow, D., Shelby-James, T., Plummer, J. & Sanderson, C. (2008). Preference for place of care and place of death in palliative care: are these different questions? *Palliative Medicine* 22(7), 787–795.

Age UK (2016). *End of life policy position paper*. London: Age UK.

Care Quality Commission (CQC) (2016). A different ending. Addressing inequalities in end of life care. Available online at: https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf [Accessed 10.09.18]

Catt, S., Blanchard, M., Addington-Hall, J., Zis, M. & Blizard, R. (2005). Older adults' attitudes to death, palliative treatment and hospice care. *Palliative Medicine,* 19(5), 402–410.

Department of Health (2005). *Mental Capacity Act*. London: HMSO.

Department of Health (2008). *End of Life Care Strategy*. Available online at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf.

Department of Health (2014). *Five Year Forward View*. London: HMSO.

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: HMSO.

Department of Health (2017). *One year on. The Government Response to the Review of Choice in End of Life Care*. London: HMSO.

Department of Health (2019). The NHS long-term plan. Available at: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf [accessed 24.10.20]

Department of Health, Social Services and Public Safety (2010). *Living Matters, Dying Matters Strategy: A Palliative and End of Life Care Strategy for Adults in Northern Ireland.* Department of Health, Social Services and Public Safety: Belfast. Available online at: www.dhsspsni.gov.uk/8555_palliative_final.pdf. [Accessed 11.7.17].

Gott, M., Frey, R., Wiles, J., Rolleston, A., The, R., Moeke-Maxwell, T. & Kerse, N. (2017a). End of life care preferences among people of advanced age: LiLACS NZ. *BMC Palliative Medicine*, 16:76.

Gott, M., Wiles, J., Moeke-Mazwell, T., Black, S., Williams, L., Kerse, N. & Trussardi, G. (2017b). What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers. *Palliative Medicine*, 32(1), 268–275.

Healthcare Improvement Scotland (2018). *Living well in Communities with Frailty: Evidence for what works.* Improvement Hub.

Hoare, S., Morris, Z., Kelly, M., Kuhn, I. & Barclay, S. (2015). Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLoS ONE*, 10(11).

House of Commons Health Committee (2015). *Health Committee: End of Life Care: Fifth Report of Session 2014*–15. London: The Stationery Office Limited. Available online at: www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf [Accessed 10.09.18].

Institute for Public Policy Research (2018). *End of life care in England. A briefing paper*. London: IPPR.

Kellehear, A (2005). *Compassionate Cities. Public health and end of life care*. London: Routledge.

Kellehear, A. (2015) *Compassionate city charter*. Available online at: https://www.compassionate-communitiesuk.co.uk/the-compassionate-city-charter [Accessed 24.10.21].

Kellehear, A (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM*, 106(12), 1071–1075.

Leadership Alliance for the Care of Dying People (2014). *One chance to get it right. Improving people's experience of are in the last few days and hours of life*. Available online at: https://www.mendeley.com/viewer/?fileId=5d2c1396-91ee-f3cb-7619-6999fca20cb7&documentId=2e0e4a38-7a76-31eb-b19a-890400376763 [Accessed 10.09.18].

Marie Curie (2014). *Living and dying with dementia in England: Barriers to care*. Available online at: www.mariecurie.org.uk/globalassets/media/documents/policy/policypublications/december-2014/dementia-report.pdf [Accessed: 10.09.18].

Marie Curie (2016). *Briefing End of life care audit: Dying in Hospital.* Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/england-briefings/rcp-end-of-life-care-audit-marie-curie-briefing-england-may2016.pdf [Accessed 24.10.20].

Macmillan (2013). *Time to choose. Making choice at the end of life a reality*. Available online at: https://www.macmillan.org.uk/documents/getinvolved/campaigns/endoflife/timetochoose.pdf [Accessed 10.09.18].

National Council for Palliative Care (2014) *The end of life care strategy: New ambitions*. Available online at: http://www.ncpc.org.uk/sites/default/files/End%20of%20Life%20Care%20Strategy%20New%20Ambitions%20Report_WEB.pdf [Accessed 10.09.18].

National Institute for Clinical Excellence (2011). End of life care for adults. Available online at: www.nice.org.uk/guidance/QS13/chapter/introduction-and-overview [Accessed 10.9.18].

Neuberger, J. (2013) *More care, less pathway. A review of the Liverpool Care Pathway*. Available online at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed 09.11.17].

NHS Scotland (2008). *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland*. The Scottish Government: Edinburgh. Available online at: www.gov.scot/Publications/2008/10/01091608/0 [Accessed: 09.11.17].

NHS Wales Health Board (2013). *Together for Health: Delivering End of Life Care.* NHS Wales: Cardiff. Available online at: www.wales.nhs.uk/sitesplus/documents/862/Together_for_Health-Delivering_End_of_Life-Care.pdf [Accessed: 09.11.17].

Sue Ryder (2016). *On the Brink: The future of end-of-life-care*. Available at: https://cicelysaundersinternational.org/new-report-on-the-brink-the-future-of-end-of-life-care/ [Accessed 24.10.20].

Appendix 2: Literature review 1: search strategy, flow chart, matrix

Literature review 1: search strategy

Systematic search strategy was applied – based on PRISMA model (cite).

EBSCO including Abstracts in social gerontology, Academic search complete, Cinhal and Medline. Also, Google Scholar, Pubmed, Scopus and Zetoc. Slightly different way of searching in each as have different Boolean phrases.

Specifically looking for studies similar to my own to find out what is already known in the area and what gaps there are…how studies were carried out.

08.06.17 EBSCO

S1 Hospital discharge OR Discharg* OR 'fast track' 460,293

S2 'Palliative care' OR 'end of life care' OR palliative OR terminal 733,367

S3 Perception* OR experience* OR view* OR insight OR opinion* 4,624,272

S1 + S2 + S3 = 1,071

Filter 10yrs = 715

English language = 679

Iterative process to look for additional terms to make search more expansive

As there were still too many I looked at the Thesaurus Term option and selected:

Palliative treatment

Hospital admission and discharge

Terminal Care

Interviewing

Terminally ill

Discharge planning

131. Many articles were related to decision making, communication, experiences before or after discharge but not about the discharge itself, paediatrics, interventions and their

outcomes for those at the end of life and clinical psychology models of practice. These articles were not selected.

10 articles selected.

08.06.17 Google Scholar

(~discharge AND (“palliative care” OR “end of life” OR palliative OR terminal AND ~hospital)

AND

(~perception OR ~experience OR ~view OR ~insight OR ~opinion)

253,000

Filter 2007–2009 = 31,300

AND transition = 16,700

Tried reducing the amount of terms:

“hospital discharge” AND (“end of life care” OR palliative) AND interviews = 6,840

AND transition = 4,350

Filter 2007–2017 = 5,330

Viewed 111. Many documents about advance care planning.

Then put this into **EBSCO** = 11 with only 1 new one.

08.06.17 Scopus

“hospital discharge” AND (palliative OR “end of life”) AND interview

Filter 2007–2017 = 47

English = 41

Many are the same as in EBSCO search. 2 are new but 1 cannot find full text.

“hospital discharge” OR discharge

(search within results) AND palliative OR “end of life”

(search within results) AND interview

Filter English = 463

2007–2017 = 370

Include Health Professionals, Medicine, Nursing, Social Science = 283

Found filters hard to use so looked at all 283. 4 extra articles found that had not been found in previous searches.

Tried to look at “Fast Track” but it has too many different meanings as is used in cardiac pathways and hip replacement pathways.

13.06.17 PubMed

Repeated EBSCO search = 601

Then tried changing S3 to ‘interview*’ which cut out the audits and other irrelevant interventions but encompassed views, opinions, experience, perception, insight.

= 142

Filter 10 years = 102

2 downloaded. 2 already found in previous searches.

13.06.17 Zetoc

“hospital discharge” AND (palliative OR “end of life”) AND interview = 0

“hospital discharge” AND palliative AND interview = 2 both about interventions

“hospital discharge” AND “palliative care” = 22. 1 of interest re complex palliative care needs and delayed discharge but is an audit.

Records identified through database searching (not including Google) = 579

Additional records identified through other sources = 24

Some articles were found during the scholarship application process and during the writing of the protocol. Further articles were found by looking at the bibliographies of key journal articles and book chapters.

Records after duplicates removed = 601

Records screened = 601

Records excluded = 182

Full text articles assessed for eligibility = 28

Studies included in qualitative synthesis = 24

Themes:

Palliative/eol + GT + multiple perspectives = 1 study (found Transitions study via a bibliography)

Pallitaive/eol +GT

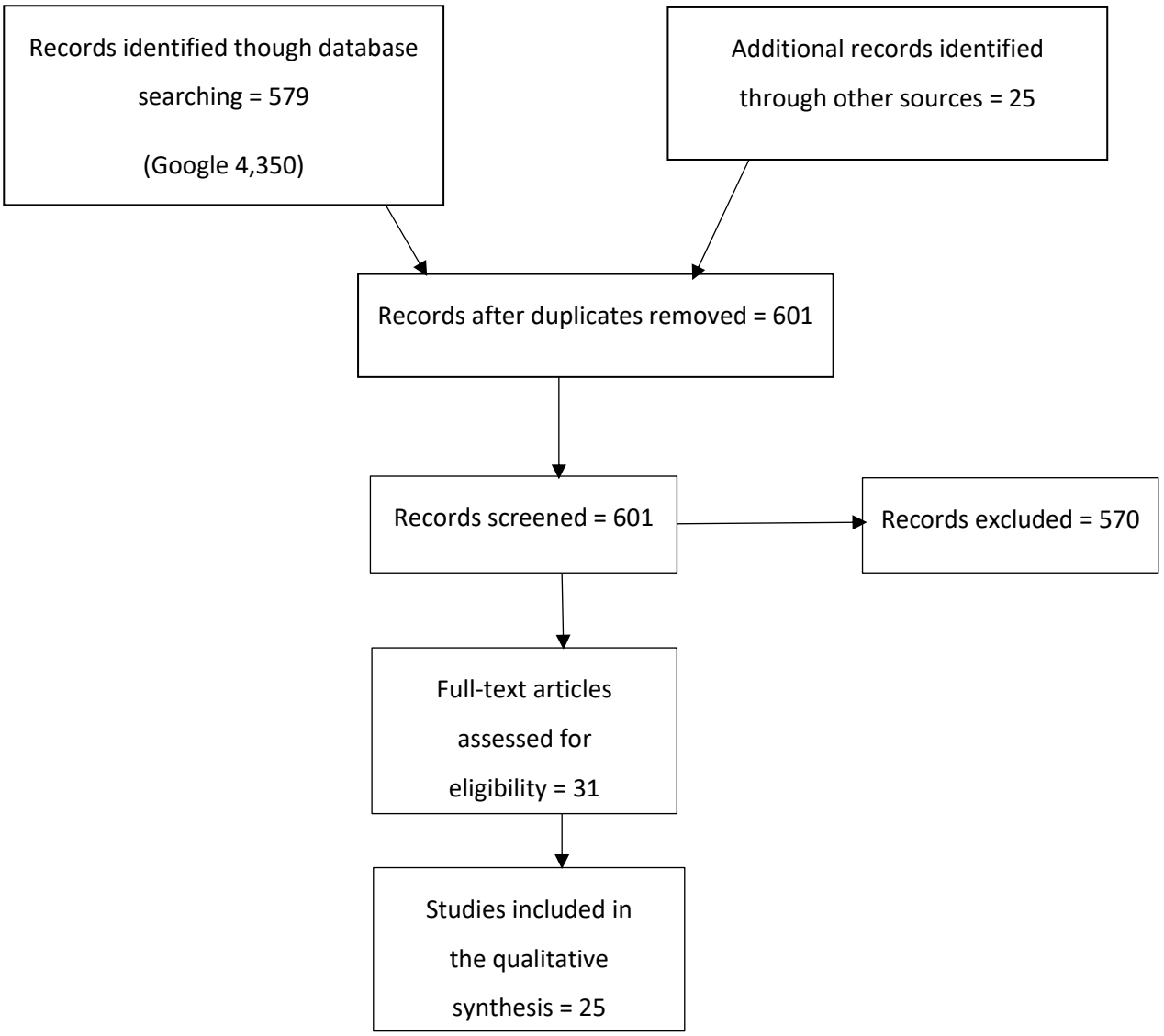
Palliative/eol + interviews

Palliative/eol + other method

Palliative/eol + discharge + qualitative

Other interesting studies – fast track.

Literature search 1 flow diagram



Literature search 1 matrix, which was looking at discharge from hospital at the end of life with an emphasis on studies that sought stakeholder perspectives

Author(s)	Reason for choosing	Key findings
Hanratty et al (2012)	**Older adults' experiences** during **transitions**, including discharge from hospital. All judged to be in **last year of life**. Heart failure, lung cancer and stroke diagnoses rather than frailty.	When older adults moved between settings institutional processes are prioritised, lack of support across settings, patients feeling unheard and lack of dignity. As well as lack of liaison across settings.
Hanratty et al (2014)	**Older adults** and their **carer's experiences** of transitions, including discharge from hospital. All judged to be in **last year of life**. Heart failure, lung cancer and stroke diagnoses rather than frailty.	Experience of disjointed system, organisational processes prioritised over individual need, carers felt unheard and unsupported with little control. Carers were 'pivotal' to patient experience. Poor communication across settings. Impact of professional tensions.
Marston et al (2015)	**Interviews** with **patient and carer**, following discharge from **hospital palliative** care unit.	All carers were female. Difficulty differentiating between professional roles. Perceived the discharge process as a shared responsibility between themselves and clinicians. Adapting to discharge home involved coping with uncertainty which is further complicated by lack of understanding of professional roles.
Benzar et al (2011)	**Interviews** with **palliative** care **patients and their carers** after **discharge.**	Gaps in discharge planning not only decrease quality of life for patietns, but also translate into lack of support for carers.

Manson et al (2017)	**Post-discharge interviews** to explore **patient experiences** in the days and weeks after discharge and diagnosis of spinal cord compression due to metastatic cancer. Not expressly end of life, but such patients will not have a long prognosis.	Highlights concerns of patients who are facing significant changes in their lives. Planning and decision making needs to consider the provision of services that are available to support patients during the transition from hospital to home.
Adam (2000)	**Views of carers** regarding how prepared they feel about **caring for a terminally ill family member after hospital discharge**.	Carers require support to care for the terminally ill at home which needs to be planned during discharge planning.
Tan et al (2016)	**Nurse views** regarding **discharge of terminally ill patients to their home**.	Nurses experience challenges in discharging imminently dying cancer patients home due to time limitations and complex needs of patients and their families. Early implementation of palliative care and a discharge pathway recommended.
Coombs et al (2015)	**Doctor's and nurse's views** regarding **discharge** from critical care **home to die.**	Transfer home from critical care is rare. Challenges to service provision include patient care needs, uncertain time to death and the view that transfer to community services is a complex, highly time-dependent undertaking.
Moback et al (2011)	Audit of fast-track **discharge** service to enable patients to **die at home**.	Fast-track service was found to be effective in achieving preferred place of death.

Appendix 3: Literature review 2: search strategy, flow chart, matrix

Search 2 research strategy

11.04.20 Google Scholar – learnt about the 'allintext' command.

allintext:"end of life" hospital +discharge +frail – 9,680 – 11.4.20

screened 70 – eligible 3

EoL, frail, hospital dc and preferably stakeholder views/interviews

11.04.20 Ebsco inc cinhal and pubmed

"aged" OR " "frail" OR "elderly" OR "geriatric"

AND

hospital AND discharge OR "hospital discharge" OR " patient discharge"

AND

"end of life" OR " terminal OR dying 3,260

Last 10 years 2,068

Full text 1,784

English 1,777

Academic journals 1,739

Aged 65+ and Aged 80+ 290 290 screened – 1 downloaded

11.04.20 Scopus

"hospital discharge" AND " frail" AND "end of life" 0

11.04.20 Zetoc

"hospital discharge" AND " frail" AND "end of life" 2

11.04.20 Pubmed

"aged" OR " "frail" OR "elder" OR "geriatric"

AND

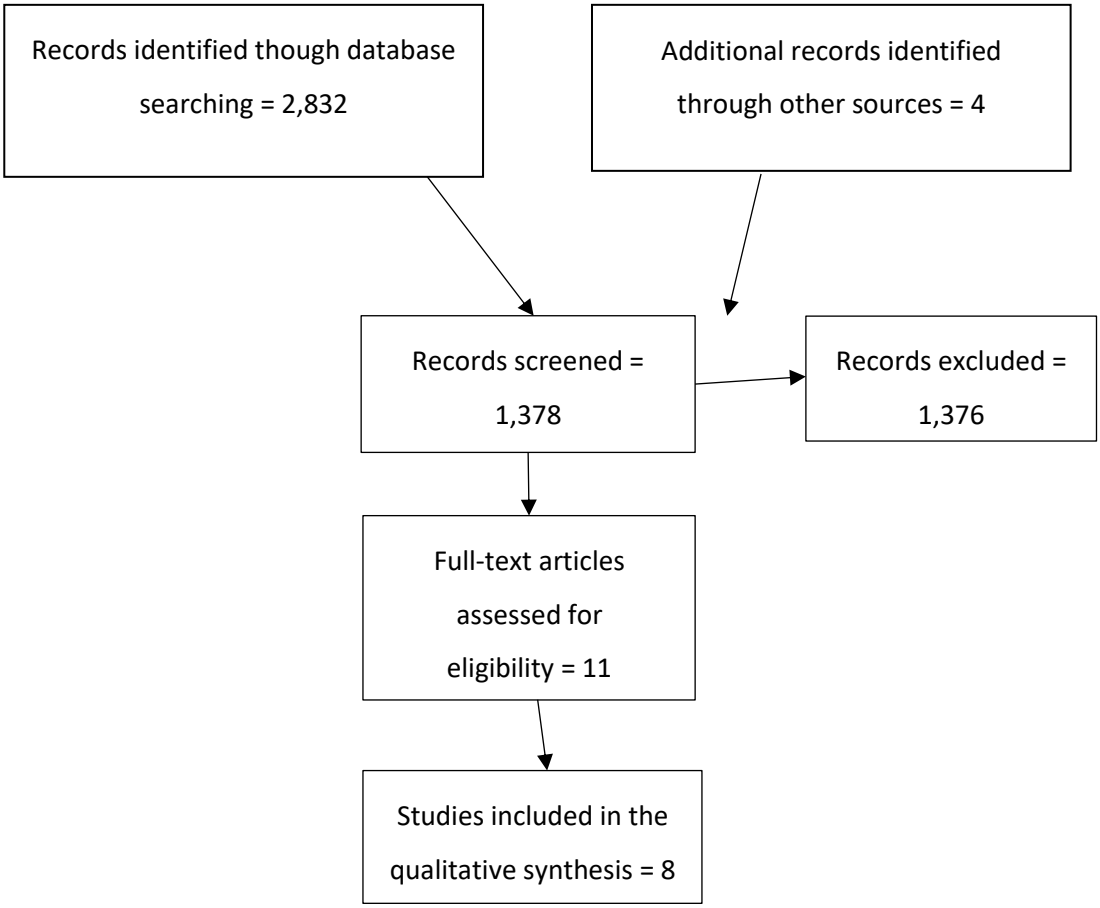
hospital AND discharge OR "hospital discharge" OR " patient discharge"

AND

"end of life" OR " terminal OR dying 1021 screened – 1 downloaded

Articles found via Twitter – 4

Literature search 2 flow diagram



Literature search 2 matrix with emphasis on older people, frailty, end of life and discharge

Author(s)	Reason for choosing	Key findings
Gott et al (2017a)	**End of life, advanced age**. Not discharge but gives insight into what is important to older people re where they want to be cared for at the end of life. Interviews.	Home death not in top three end of life priorities for older people. Top concern – not being a burden – had received little research or policy attention. Pay attention to diversity and how preferences are formulated.
Gott et al (2004)	**Older people's view re place of care at the end of life**. Does not include discharge but home is common discharge destination and is assumed to be the best place. Old study but relevant findings. Interviews.	Factors older people associate with 'home' as critical to a good death are presence of friends and family. Many anticipate that they would prefer to be cared for elsewhere when dying. Findings run counter to assumptions that a medicalised, institutional death cannot be a 'good death'.

Author(s)	Reason for choosing	Key findings
Baillie et al (2014)	**Discharge, frailty**. Case study including interviews with **acute and community ward staff as well as patients with frailty**. No end of life.	Boundaries between staff in different settings remained a barrier to transitions, as did capacity issues in community healthcare and social care. Staff in acute and community settings need opportunities to gain better understanding of each other's roles and build relationships and trust.
Bauer et al (2009)	Literature review re **hospital discharge** planning for **frail older people**. No interviews	Discharge planning for frail older people can be improved through family inclusion, communication between health professionals and family, interdisciplinary communication and ongoing support after discharge.
Ewing et al (2018)	**Carers, hospital discharge at the end of life**. Includes **hospital and community health professionals** as well as carer **interviews**. No frailty.	Barriers to supporting carers at discharge were an organisational focus on patients' needs, practitioner perception of carers' 'unreasonable expectations' and lack of awareness of the patients' situation at end of life.
Hestevik et al (2019)	**Older people experiences** of life after **discharge**. Meta summary of qualitative studies. No end of life.	Importance of assessment and planning, information and education, preparation of the home environment, involvement of the older person and carer, and follow-up care at home. Communication and coordination between services to facilitate recovery at home.
Huijberts et al (2015)	**End of life, frailty, during and after hospital admission**. Cohort study from patient records.	Patients with frailty were not identified as approaching the end of life. In general, patients with cancer had the highest rates of healthcare utilisation.
Popejoy (2011)	**Discharge, older people, family, health professionals, decision making re discharge**. Interviews. No end of life.	Older females may not feel comfortable voicing their opinion to dominant family members. 46% of families report no involvement in discharge planning. If family are involved in discharge planning problems with the discharge plan may come to light earlier.

Appendix 4: Patient consent to be contacted after discharge form

Permission to contact me or my family

Yes, I am happy for a researcher to contact me

Your name……..

Your address……...
……
……

Your telephone phone number……...

Or email……..

I would prefer the researcher to contact a family member or friend who cares for me.

The name of the person who cares for you……..

Their address……...
……
……

Their telephone phone number……...

Or email……..

Permission_v1_060617

Appendix 5: Patient, carer and health professional information leaflets

CHSS
University of Kent
George Allen Wing
Canterbury
Kent CT2 7NF

PATIENT INFORMATION SHEET

Study: **What enables discharge from hospital to the community?**

We would like to invite you to take part in a research study that is being carried out by Emily Mckean who is a PhD student at the University of Kent. The other researchers are Professor Patricia Wilson and Professor Claire Butler who are supervising the research. The PhD study will explore your experience of being discharged from hospital. It will aim to explore and understand what processes are involved in the discharge of someone who has recently been unwell enough to need admission to hospital and has been requiring more care and support at home.

Before you decide whether to take part you need to understand why the research is being carried out and what it involves. Please take time to read the following information carefully. Please ask if anything is unclear or you would like more information; our contact details are at the end of this sheet. The study is being supported by East Kent Hospitals University Foundation Trust, Kent Community Health Trust, your GP practice, and funded by the University of Kent.

What is the purpose of the research?

The study plans to explore and understand what processes are involved in the discharge from hospital of someone who has been requiring more support at home, and how this is experienced by everyone involved. As well as including you, it may also include your family or carer as well as your health professionals in the hospital and in the community. We want to build a complete picture of what happens with a view to ensuring a good experience for future patients, families and health professionals.

Why have I been invited?

You are being asked to take part because you are being discharged from hospital to your home, or some other community setting, for example a nursing home or the hospice. We would like to learn about your experiences now you are home. If you have a close relative who helps you, we would also like to learn about their experiences. We would also like to know about the experience of the hospital staff who facilitated your discharge, and those in the community who take part in your care now.

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How will I be involved in the project?

Taking part in the research means you will have the opportunity to tell the researcher about your experiences following your discharge home from hospital. The researcher will visit you where you currently live to interview you. This is not formal but more like a conversation. The interview will be as soon after your discharge as possible so your memories of the experience are fresh. However, if you do not feel up to visitors this can be delayed to a date of your choice. The interview will take as long as you feel able to participate. We want to allow you to express your experiences without overtiring you, which means interviews may take anywhere between 30 and 90 minutes. It is entirely up to you how long you spend talking about your experiences.

If you agree to take part, we will contact you to arrange the interview on a day and time that suits. We also want to learn about your close relatives' experiences. We will ask you if you are happy to talk together or are more comfortable speaking separately. We will also ask if you are happy for us to interview the key members of staff involved in your care just before and after discharge, to gather their experiences of the process also.

We would like to record the interview using a Dictaphone to help us remember what you say. Before we start recording we will ask you to sign a consent form agreeing to take part. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes from the interview when writing up the research but any names will be removed.

Do I have to take part?

No. It is up to you whether or not to take part. If you decide to take part you can change your mind at any time without giving a reason. A decision not to take part will not affect your care and treatment in any way.

Are there benefits to taking part?

There are no immediate benefits of this research to you but it may help people in a similar situation to you in the future. The research is hoping to make a valuable contribution to how people who are receiving extra care and support are discharged from hospital in the future: making the experience better for everyone involved in the process.

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What might be difficult about taking part?

You may find the interview tiring or you may find it upsetting to talk about your experiences. You can stop the interview at any time. We will provide you with information about support available locally if you feel you need it.

Will my taking part in this project be kept confidential?

If you decide to take part all information collected from you will be kept strictly confidential. The recording of your interviews will be deleted after we have typed them. The paperwork will be stored in a protected way so that you cannot be identified. Only the researcher and her supervisors will have access to this information.

If you tell us something that indicates there is a risk of harm to yourself or someone else, then we will need to consider telling someone about this risk. We will not speak to anyone without discussing with you first.

What will happen to the results of the research?

This study will help us understand your experiences and the experiences of those caring for you. This will help to improve the discharge process in the future. We will share what we have found out with everyone who was involved in the study, including you and those caring for you, the Hospital and Community Trusts and any other non-NHS services that have supported you. In order to reach a wider audience the results might be published in academic journals and presented at academic or professional conferences. You will not be identified in any way.

What next?

If you would like to take part, please fill in the permission slip and return in the stamped addressed envelope. We will contact you to make an appointment for the interview when we receive the permission slip. If you have any questions please feel free to contact the researcher, **Emily Mckean,** PhD student, University of Kent. Email: ejbm2@kent.ac.uk**. Tel: 07716582088.**

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Questions or concerns?

The study has been reviewed and approved by King's Cross and Camden NRES Committee. The reference is 17/LO/0854. If you have any concerns/complaints please contact the researcher directly. If the issue is not resolved successfully please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229.

The Hospital Trust has a Patient Advice and Liaison Service which can be contacted at:

First Floor, Trust Offices, Kent and Canterbury Hospital, Ethelbert Road, Canterbury, CT1 3NG

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FAMILY/CARER INFORMATION SHEET

Study: **What enables discharge from hospital to the community?**

We would like to invite you to take part in a research study that is being carried out by Emily Mckean who is a PhD student at the University of Kent. The other researchers are Professor Patricia Wilson and Professor Claire Butler who are supervising the research. The PhD study will look at what enables discharge from hospital to the community. It will aim to explore and understand what processes are involved in the discharge of someone who has recently been unwell enough to need admission to hospital and has been requiring more care and support at home.

Before you decide whether to take part you need to understand why the research is being carried out and what it involves. Please take time to read the following information carefully. Please ask if anything is unclear or you would like more information; our contact details are at the end of this sheet. The study is being supported by East Kent Hospitals University Foundation Trust, Kent Community Health Trust, your GP practice, and funded by the University of Kent.

What is the purpose of the research?

The study plans to explore and understand what processes are involved in the discharge from hospital of someone who has been requiring more support at home, and how this is experienced by everyone involved. This will include the patient, you as their family or carer, and the health professionals in the hospital as well as those in the community. We want to build a complete picture of what happens during the discharge process with a view to ensuring a good experience for future patients, families and health professionals.

Why have I been invited?

You are being asked to take part because you live with or are caring for someone who is being discharged from hospital to their home, or some other community setting, who has been requiring more care and support recently. We will only ask to talk to you if the patient agrees they are happy for us to discuss your experience with us.

How will I be involved in the project?

Taking part in the research means you will have the opportunity to tell the researcher about your experiences following the discharge home from hospital. The researcher will visit you at home (or

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other setting convenient for you) to interview you. This is not formal but more like a conversation and will be soon as possible after discharge, so your memories of the experience are fresh. However, if you do not feel up to visitors this can be delayed to a date of your choice. As a guide, the whole visit could take between 30 and 90 minutes but the interview itself will take as long as you feel is appropriate, with time for questions, although this is at your discretion.

If you agree to take part, we will contact you to arrange the interview on a day and time that suits. The patient may want to be present for the interview so we will ask them their preference.

We would like to record the interview using a Dictaphone to help us remember what you say. Before we start recording we will ask you to sign a consent form agreeing to take part. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes from the interview when writing up the research but any names will be removed.

Do I have to take part?

No. It is up to you whether or not to take part. If you decide to take part, you can change your mind at any time without giving a reason. A decision not to take part will not affect the patient's care and treatment in any way.

Are there benefits to taking part?

There are no immediate benefits of this research to you but it may help people in a similar situation in the future. The research is hoping to make a valuable contribution to how people are discharged from hospital in the future: making the experience better for everyone involved in the process.

What might be difficult about taking part?

You may find it upsetting to talk about your experiences. You can stop the interview at any time. We will provide you with information about support available locally if you feel you need it.

Will my taking part in this project be kept confidential?

If you decide to take part all information collected from you will be kept strictly confidential. The recording of your interviews will be deleted after we have typed them. The paperwork will be stored

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in a protected way so that you cannot be identified. Only the researcher and her supervisor will have access to this information.

If you tell us something that indicates there is a risk of harm to yourself or someone else then we will need to consider telling someone about this risk. We will not speak to anyone without discussing with you first.

What will happen to the results of the research?

This study will help us understand not only the patient's experiences but also of those close to them and of those caring for them. This will help to improve the discharge process in the future. The researcher will send you a summary of the findings and you are welcome to discuss them with her. The results will be available for everyone who has taken part including yourselves, the Hospital and Community Trusts and any other non-NHS services that have supported the patient, for example the Hospice. In order to reach a wider audience the results might be published in academic journals and presented at academic or professional conferences. You will not be identified in any way.

What next?

If you have any questions please feel free to contact the researcher, **Emily Mckean,** PhD student, University of Kent. Email: ejbm2@kent.ac.uk**. Tel: 07716582088.** Otherwise we will contact you to see if you agree to take part. If you do agree, we can make an appointment for the interview.

Questions or concerns?

The study has been reviewed and approved by King's Cross and Camden NRES Committee. The reference is 17/LO/0854.

If you have any concerns/complaints please contact the researcher directly. If the issue is not resolved successfully please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229.

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HEALTH PROFESSIONAL INFORMATION SHEET

Study: **What enables discharge from hospital to the community for people in the last weeks/months of life?**

We would like to invite you to take part in a research study that is being carried out by Emily Mckean who is a PhD student at the University of Kent. The other researchers are Professor Patricia Wilson and Professor Claire Butler who are supervising the research. The PhD study will explore your experience of being discharged from hospital. It will aim to explore and understand what processes are involved in the discharge of someone who is in the last weeks or months of life.

Before you decide whether to take part you need to understand why the research is being carried out and what it involves. Please take time to read the following information carefully. Please ask if anything is unclear or you would like more information; our contact details are at the end of this sheet. The study is being supported by East Kent Hospitals University Foundation Trust, Kent Community Health Trust, the patient's GP practice, and funded by the University of Kent.

What is the purpose of the research?

The study plans to explore and understand what processes are involved in the discharge from hospital of someone who is in the last weeks or months of life, and how this is experienced by all stakeholders. This may include the patient, their family or carer but also their health professionals in the hospital as well as those in the community. We want to build a complete picture of what happens during the discharge process with a view to improving the experience for future patients, families and health professionals.

Why have I been invited?

You are being asked to take part because you were involved in the care of someone who is in the last weeks or months of life and was discharged from hospital to a community setting. We would like to learn about your experiences of the discharge process. We have asked the patient for their permission to talk to you about the discharge process.

How will I be involved in the project?

Taking part in the research means you will have the opportunity to tell the researcher about your experiences of the patient's discharge back to the community from hospital. The researcher will visit

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you to interview you at a place most convenient for you, such as your workplace. This is not formal but more like a discussion. The interview will be as soon as possible after the patient's discharge so your memories of the experience are fresh. However, if you are too busy the interview can be delayed to a date of your choice. The interview will take 20 minutes with time either side for questions. The whole visit will take no longer than 30 minutes.

If you agree to take part, we will contact you post discharge to arrange the interview on a day and time that suits. We would like to record the interview to help us remember what you say. Before we start recording we will ask you to sign a consent form agreeing to take part. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes from the interview when writing up the research but any names will be removed.

Do I have to take part?

No. It is up to you whether or not to take part. If you decide to take part you can change your mind at any time without giving a reason. A decision not to take part will not affect your employment in any way.

Are there benefits to taking part?

There are no immediate benefits of this research to you but it may make a valuable contribution to how people who are receiving palliative care are discharged from hospital in the future: making the experience better for everyone involved in the process.

What might be difficult about taking part?

You may find it upsetting to talk about your experiences. You can stop the interview at any time. We will provide you with information about support available.

Will my taking part in this project be kept confidential?

If you decide to take part all information collected from you will be kept strictly confidential. The recording of your interview will be deleted after we have typed them. The paperwork will be stored in a protected way so that you cannot be identified. Only the researcher and her supervisors will have access to this information.

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If you tell us something that indicates there is a risk of harm to yourself or someone else then we will need to consider telling someone about this risk. We will not speak to anyone without discussing with you first.

What will happen to the results of the research?

This study will help us understand your experiences of the discharge process. This will help to improve the discharge process in the future. The researcher will send you a summary of the findings and you are welcome to discuss them with her. The results will be fed back to the patient and their family as well as the Hospital and Community Trusts and any other non-NHS services that have supported them, for example the Hospice. In order to reach a wider audience the results might be published in academic journals and presented at academic or professional conferences. You will not be identified in any way.

What next?

If you have any questions please feel free to contact the researcher, **Emily Mckean,** PhD student, University of Kent. Email: ejbm2@kent.ac.uk**. Tel: 07716582088.** Otherwise we will contact you to see if you agree to take part. If you do agree, we can make an appointment for the interview.

Questions or concerns?

The study has been reviewed and approved by King's Cross and Camden NRES Committee. The reference is 17/LO/0854.

If you have any concerns/complaints please contact the researcher directly. If the issue is not resolved successfully please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229.

Appendix 6: Patient, carer and health professional consent forms

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CONSENT FORM FOR PARTICIPANTS

Title of Project: What enables discharge from hospital to the community?

Name & contact details of researcher: Emily Mckean, CHSS, George Allen Wing, University of Kent, Canterbury, Kent CT2 7NF. Tel: 01227 824057. Email: ejbm2@kent.ac.uk

IRAS: 194007

Participant Identification Code for this study:	Please initial box
1. I confirm that I have read and understand the information sheet dated 13.8.18 (version 4) for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	☐
3. I understand that everything I say is confidential unless I tell you something that indicates that I, or someone else, is at risk of harm in which case you would discuss this with me before telling anyone else.	☐
4. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.	☐
5. I understand and agree that the interview will be audio-recorded.	☐
6. I agree to my family/carer taking part	☐
7. I agree to key health professionals involved in my discharge being interviewed.	☐
8. I agree to take part in the above study.	☐

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9. I agree to be contacted for another interview to talk about life after discharge from hospital ☐

Name of Participant _____ Signature _____ Date_____

Name of Researcher _____ Signature _____ Date_____

Copies: 1 for participant, 1 for researcher, 1 for patient community notes.

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CONSENT FORM FOR PARTICIPANTS

Title of Project: What enables discharge from hospital to the community?

Name & contact details of researcher: Emily Mckean, CHSS, George Allen Wing, University of Kent, Canterbury, Kent CT2 7NF. Tel: 01227 824057. Email: ejbm2@kent.ac.uk

IRAS: 194007

Participant Identification Code for this study:

	Please initial box
1. I confirm that I have read and understand the information sheet dated 13.8.18 (version 4) for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	☐
3. I understand that everything I say is confidential unless I tell you something that indicates that I, or someone else, is at risk of harm in which case you would discuss this with me before telling anyone else.	☐
4. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.	☐
5. I understand and agree that the interview will be audio-recorded.	☐
6. I agree to take part in the above study.	☐
7. I agree to be contacted about giving another interview to talk about life after the discharge from hospital.	☐

I do/do not* wish to receive a summary of the results.

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*delete as applicable

Name of Participant _____ Signature _____ Date_____

Name of Researcher _____ Signature _____ Date_____

Copies: 1 for participant, 1 for researcher

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CONSENT FORM FOR PARTICIPANTS

Title of Project: What enables discharge from hospital to the community for people in the last weeks or months of life?

Name & contact details of researcher: Emily Mckean, CHSS, George Allen Wing, University of Kent, Canterbury, Kent CT2 7NF. Tel: 01227 824057. Email: ejbm2@kent.ac.uk

IRAS: 194007

Participant Identification Code for this study:

	Please initial box
1. I confirm that I have read and understand the information sheet dated 13.8.18 (version 4) for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	☐
3. I understand that everything I say is confidential unless I tell you something that indicates that I, or someone else, is at risk of harm in which case you would discuss this with me before telling anyone else.	☐
4. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.	☐
5. I understand and agree that the interview will be audio-recorded.	☐
6. I agree to take part in the above study.	☐
7. I agree to being contacted about giving another interview about life after the discharge from hospital.	☐

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Name of Participant _____ Signature _____ Date_____

Name of Researcher _____ Signature _____ Date_____

Copies: 1 for participant, 1 for researcher

Appendix 7: Interview guide

The interview guide was loosely based on Hanratty et al (2014) *Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study* for quality purposes, as this was a large NIHR study. Allowed conversation to flow, therefore questions were not answered in order, but I would refer to the interview guide to ensure no questions were missed.

- Introductions: researcher name. PhD student at UKC. Thank for taking part. Remind can withdraw at any time.
- Outline study purpose and provide information sheet.
- Consent form. If patient – request permission to speak to main carer(s) and health professionals. Check box if summary of results desired.
- Ask participant to summarise how was living before admission and what lead to hospital admission. Include family input received/given before hospital admission.
- Ask participant to describe reason for transfer to community hospital.
- Discuss experience in hospital and how discharge was approached and experienced.
- Which health professionals were involved in the discharge – before and after?
- What were thoughts on discharge – good and bad?. What could have been done differently to improve it?
- How is life after discharge? What services are involved – social care, community nursing, ICT and so on? Was there a delay? Any issues?
- End. Confidentiality. Anonymous data. Ability to withdraw at any time. Use of results without names.

Sources of support information sheet provided if participant is seeking more support.

Appendix 8: Field note extract

P2.H1 and P2.H2

x.x.19

OT and PT

Shining through is how daughter was the lynch pin and took considerable burden to ensure successful discharge. Still taking burden in the community also coordinating all the services etc.

OT/PT able to successfully treat without digging around in psychological issues regarding breast cancer and metastases. Treated patient and daughter anxiety and mobility issues that were presenting and respected patient's wish to not talk about new life limiting diagnosis.

OT/PT reporting daughter overloaded and had a lot of questions which they made sure to answer in order to ameliorate anxiety. OT took patient home to check OK with new living arrangements and equipment appropriate. Due to anxiety regarding the discharge home the hospital bed was kept open for patient to return if it was not working out at home – safety net. Report this was reassuring for patient and daughter. Daughter called after discharge to say thank you.

Appendix 9: Interview extract with line by line coding

P2.F2

So, the study is about discharge from hospital and it sounded like you were really, really important in the discharge from hospital, so I was hoping to talk to you about your experience of it.

Right. So is it actually just the discharge or what's happened since?

Well, I was discussing that with my supervisor and if the care is set up in the hospital for you to carry on at home, then I feel that the care is kind of part of it, and also if you weren't here and the care is failing there's a good chance she would then end up in hospital again isn't there, so just tell me about whatever... We could start at the beginning.

OK.

So she had her fall...

Yeah, in, well end of August it was, beginning of September. She went to [xxx] Hospital, she was in there for about, I can't remember, probably a week, two weeks, just, probably two weeks, then she went to the [xxx] at Herne Bay.

Care @ home rather than temporary RH placement to cont. rehab

Yeah.

Experienced daughter disagrees with hospital rhetoric

Then they kept her there and then they said about her needing to be discharged. Now, they said rather than go for another, you know, go into a home, it would be best to come home because everything would be set up and it would be a lot easier. Well, my experience is, no, it's not easier. Luckily they did set everything up in the hospital, the occupational therapist came out, so when she came home there was the bed, the chair, so all that, all the, you know, extra stuff was here so that was good. She had the [xxx] Team who were useless, they were terrible, for a few days but they're just like the interim aren't they, before the Enablement Team. But these teams are all very hit and miss. Now I thought, because she had terminal metastatic cancer, she would be able to have continuing healthcare, which means that they would fund, and I understood that anybody that was diagnosed with less than six months, which they can't give a specific time, but she has got it in her lungs and her lymph nodes, but no, apparently unless she's breathing her last breath practically, she's, she doesn't qualify for it, but I'm not, I'm going to keep on about that because I still don't agree. So she had the Enablement Team for about five weeks, and as I say, some are better than others, and they say they're coming at a certain time and they don't always, they're not time something or other, I can't remember what they call it now. Anyway, the Social Worker came out, no it wasn't a Social Worker, the Enablement Team Supervisor came out to assess her, when she first came out of hospital she was having three calls a day, she's now been assessed that she only needs one call a day, so she's only having them in in the morning to get her up and dressed. Now I don't think she's that good at getting her lunch, so they make her a sandwich but I am coming at lunchtimes and doing her lunch, because otherwise I don't think she'll get a hot meal.

Easier to go home

hit + miss social care

variability inquality of care provided by carers

vocal fighting for mum

carer burden

Right.

social care process removing control whilst ↑ reliance on daughter

being 'passed' around

Then from the Enablement Team they've now passed her over to [xxx] because they were the care package that accepted her or something. So she's had them for a week, one day they didn't turn up 'til twenty past eleven. Late first call like PTO

To get her up?

Yeah, and give her her breakfast so I got on the phone, I've been on the phone nearly every day to them. We then had Social Services ring up to find out what money she has coming in, because she has a private pension they deem that she's not entitled to any help and she's got to pay for all her care. So now I'm ringing up every time that there's something wrong saying 'we are paying for this so I expect it to be done properly'. Battling the system Time consuming stressful vigilant

Right.

Because, you know, I don't see at 87 she should have to be paying for it, she's never had a thing, it just, it's just so annoying. *[Interviewee leaves the room to answer the doorbell].*

So she's got too much pension, she's been means-tested...

Yeah.

...and she has to pay.

Yes.

And you're not very happy with what you're, the service you're receiving from [xxx]

No. No.

Have you been given any options to, if you're privately purchasing, to purchase something else? Afraid to get out of the system in case it means 'jumping through hoops'

Well this is what I'm thinking, we don't really, we could pay for a private carer really. But then I'm not sure whether that means that when the time comes, and if she deteriorates, which she will do, whether it's going to be a jumping through hoops again to get her assessed, if we go down the private route. ↓ so not doing an option that may ↓ burden

And have the hospice given you any advice about how this all pans out?

I did say to them, they were more or less the same thing, they more or less said unless she's practically literally dying, that, you know, this is the way it is, everything's, all the funding's been cut and so,. No financial help until 3 months prognosis

So you're a bit in the dark.

Mmm. Well I just think this is how it'll go on until she becomes, you know, more incapacitated and then they'll have to reassess her. uncertainty. waiting for deterioration in health.

And on the phone you were saying that you've had to take some time off work.

Yeah, I'm off work now.

To...

So...

Why's that?

signed off work as burden too great
Low mood

I've been signed off work because I've, lunchtimes I have to see her, every day it's sorting out things so if I was at work I'd have to be, plus I'm getting depressed by it all to be honest, plus I've got a partner who's terminally ill so that doesn't help.

caring for mum + terminally ill partner.

No.

So there's a lot and he's, he's probably more along than mum is really.

OK.

So they're draining his lung every day.

Right.

So he's...

At home or is he...

Yeah.

Right.

Yeah, yeah.

was looking like I could not go into more detail ther cout getting upset, so moved on.

OK, so you've got a lot on your plate.

Mmm. Yes.

OK, and not feeling terribly supported is what I'm hearing.

confusion re term "terminally ill"

Yeah. I mean, when all this happened, I rang the GP and I said to him about mum being terminally ill, so why was she not, and he said 'I do everything' he said 'oh it's terrible, I do my level best' and he did a referral but asked for her to be put into a nursing home, well she doesn't want that and nothing ever came of that anyway so I think it got as far as Social Services and it's just, every time I rang Social Services when she was under the Enablement Team, they were the only people that I got to speak to. I didn't get... now she's been allocated a Case Manager and she's meant to be coming out in December, so...

Not what was asked for

Current experiences dying/death → partner.

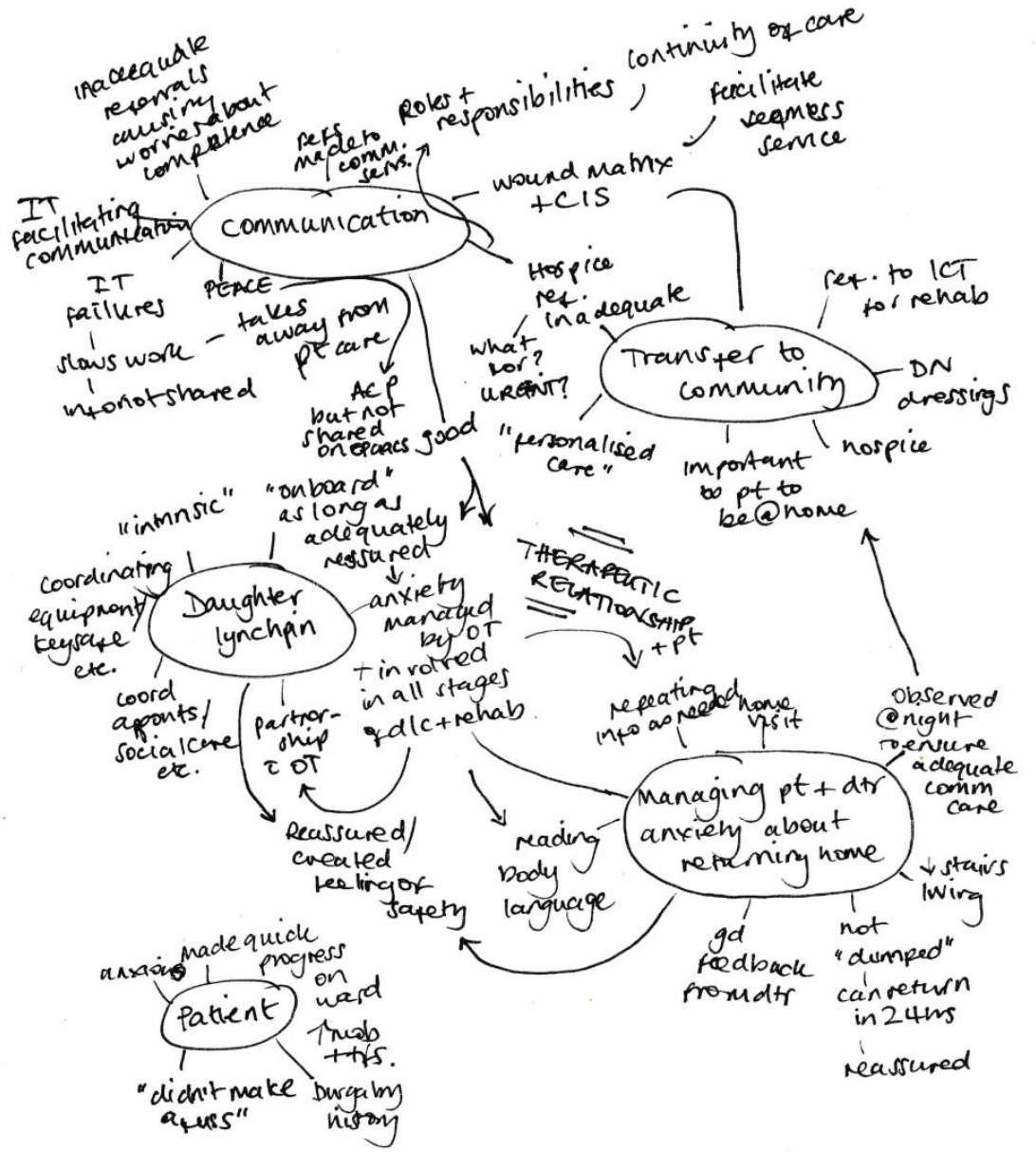
but didn't really know what was asking for — just knows she needs help/support

OK, so she's got Social Services Case Manager.

Yeah.

Appendix 10: Messy map example





Questions:

- would hospital follow up helped?
- confusion re hospice role?
- use of URGENT ↓
- Lack of trust between agencies

hospital + community health professionals

P2.H1, P2.H2, P2H.3, P2C.1

Appendix 11: Ethics review letter

NHS
Health Research Authority

Mrs Emily Mckean
Shearstone
Bladbean
Canterbury
CT4 6LU

Email: hra.approval@nhs.net

27 June 2017

Dear Mrs Mckean

Letter of HRA Approval

Study title:	**What enables discharge from hospital to the community for people requiring palliative care in the last weeks or months of life?**
IRAS project ID:	**194007**
REC reference:	**17/LO/0854**
Sponsor	**University of Kent**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

Appendix 12: Sources of support information sheet

Sources of support

If you feel that you need more support, here is a guide to some of the resources available for you.

Your GP

Community Nurse
Ashford 0300 790 0270
Canterbury 0300 123 4415
Dover 01304 865609
Shepway 01303 717044
Thanet 0300 7900 386

Intermediate care team (Occupational Therapist, Physiotherapist, Speech and Language Therapist) Canterbury 0300 123 44 15, Ashford 0300 123 09 15.

Pilgrims Hospices provide support and information 7 days a week, any time of the day or night 01233 504133.

Macmillan helpline 0808 808 00 00* for cancer specific support. *free

Hospital Palliative Nurse KCH 01227 766877 WHH 01233 633331.

Carer's Support Canterbury, Thanet and Dover 01304 364637. Support specifically for carers.

Patient advice and liaison service (PALS) 01227 864314 If something is worrying you about the care and/or treatment you received in hospital.

Community Trust customer care team 0300 123 1807 If you want advice or to give feedback regarding your health care in the community.