Walking the Frailty Tightrope:

Exploring the construction of identity in older people with frailty within an NHS Day Hospital

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A thesis submitted in partial fulfilment of the requirements of Bournemouth University for the degree of Doctor of Philosophy (PhD)

Bournemouth University

December 2020

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ABSTRACT

People with frailty are less likely to recover from illness and are at greater risk of falls, institutionalisation and death. Rates of frailty are increasing and expected to rise as the population ages putting great pressure on the NHS.

Over the last 20 years frailty has been explored in terms of biomedical assessment and intervention however authors report that older people do not necessary value or want to take part in ‘frailty’ services. Focusing on identity and sense of self, this study set out to determine how a Day Hospital providing frailty services; which were highly regarded by older people, supported people to engage in services. This ethnographic study aims to contribute to this gap in knowledge through exploration of the socio-cultural experiences of older people undergoing treatment in an NHS Day Hospital. Through approximately 100 hours of participant observations and additional focus group discussions, the cultural practices and processes, interactions and experiences of care within the Day Hospital were documented and analysed.

The findings of the study contribute knowledge in three main areas firstly; that sense of self-identity in people with frailty is constructed through numerous losses and social perceptions that shape their social roles. This can create a sense of ontological insecurity, or disruption to the order of their lives as they know them. Secondly humanising processes within the Day Hospital, supported people with frailty to feel more secure in their daily activities, social roles and identities. This was achieved through fostering a hospitable environment and building a culture of humanising relationships on embodied relational knowledge. These cultural processes contributed to older people with frailty engaging more fully in their rehabilitative journey. Finally, the study revealed that the construction of a nurturing and accepting work culture, is an essential foundation to support humanising and embodied practice for older people with frailty.

Fostering a culture where positive sense of self for both patients and staff is supported is key to continued therapeutic engagement. Changes in personal identity in people with frailty and the responses needed to address them need to be considered by policy makers and healthcare providers to provide appropriate and effective care services.

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ACKNOWLEDGEMENTS

Firstly, I would like to thank my amazing supervisory team, as without their constant commitment and support this study would not have been possible. Dr Caroline Ellis-Hill who has continually opened my mind to new possibilities and concepts and enabled me to understand and harness the power of embodied practice. Dr Michelle Board who has supplied unending energy and enthusiasm, her passion to progress the understanding of frailty and improve clinical care is evident for all to see. And to Professor Michael Vassallo who has always made time for me and imparted his wealth of experience and clinical knowledge and helped be to believe in myself. For their investment and belief in me I will be eternally grateful.

To all those I met along this journey within the Day Hospital, that kindly shared their stories and graciously opened their hearts and worlds to me. I am privileged and humbled to have met you and forever grateful for allowing me to share in this part of your lives. These experiences I will always remember and cherish. Also, to Annette Fraine, Sarah Orr and Andrea Lacey who provided practical and moral support during the collection of focus group data, and to artist Tom Filer for his patience and understanding of my scribbles and concepts, I am so very grateful for your help and time.

To my Mum and Dad who sadly did not survive to see the conclusion of this journey, I know you are looking down upon me and beaming with pride. Without your love my life would have taken a very different path. To all my extended family and friends, I truly thank you for your unending support, coffee, chocolate and love, and the sacrifices that you have had to make along this journey. I am indebted to all of you.

This work is dedicated to Amelia my daughter, who told me to *“just do it”*

..... so, I did

Amelia-Grace

27.10.01 – 24.06.10

PARTNERSHIP

This Doctoral study was jointly funded between Bournemouth University and University Hospitals Dorset (*formerly The Royal Bournemouth and Christchurch Hospital NHS Foundation Trust*). The project was part of a programme of academic work between the University and Hospital trust to enhance fusion and link education to practice. As part of the studentship I maintained my clinical practice at 15 hours per week alongside the study, the studentship was therefore spread over a four year period.

Glossary

BAME	Black, Asian, and minority ethnic (used to refer to members of non-white communities in the UK).
CFS	Clinical Frailty Scale
CGA	Comprehensive Geriatric Assessment
eFI	Electronic Frailty Index
GDPR	General Data Protection Regulation
GP	General Practitioner
HRA	Health Research Authority
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
NSFOP	National service Framework for Older People
OT	Occupational Therapist
Physio	Physiotherapist
REC	Research Ethics Council
UK	United Kingdom

Chapter 1 Setting the Scene: The changing landscape of Ageing

"There is a certain part of all of us that lives outside of time. Perhaps we become aware of our age only at exceptional moments and most of the time we are ageless."

(Kundera 1990)

People are living longer than ever before, over the next 30 years the global population of people aged over 60 years is going to more than double reaching 2 billion by 2050 (Office for National Statistics 2018a). The most rapid population growth is seen in people aged over 80 years, their numbers are estimated to almost quadruple by 2050 (World Health Organisation 2015). It is vital therefore that strategies are in place to support the needs of this population, particularly in health and social care. In Kundera's (1990) book Immortality he invites us to imagine living in a world without mirrors, we would imagine what our faces would look like, and perhaps believe that they would reflect our inner identity, in other words our own sense of self. Now imagine if at the age of 80, having not seen your own face, someone placed a mirror in front of you. Visualise your possible surprise, when presented with the face before you. Is this face the one you imagined? Would it represent you? Would it display how you feel and 'see' yourself? As we age, our sense of self-identity can be affected by the way in which others view us. We live in a world of 'societal mirrors' that not only reflect our physical appearance, but often also tell us what that appearance represents. Grey hair, wrinkles, arthritic hands, a walking stick are generally interpreted by society as representing age, vulnerability, weakness, dependency and frailty. These interpretations can be exacerbated if an older person experiences ill health or a long term condition such as frailty.

In this study I explore and contribute to the knowledge base regarding the identities of older people living with the condition of frailty. Through ethnographic exploration of the socio-cultural experiences of older people undergoing treatment in a National Health Service (NHS) Day Hospital, I seek to understand how the identities of older people living with frailty are experienced, understood and constructed within this environment. I also set out to determine key processes which can inform current and future developments in caring for people with frailty via exploration of their experiences of care and the cultural practices within the Day Hospital.

1.1 Chapter Introduction

Within this introductory chapter I will outline the background and relevance of this study against contemporary United Kingdom (UK) ageing demographics, healthcare policies and existing frailty services. I summarise what frailty is and how it is currently assessed and diagnosed, as well as outlining some of the existing support services available in the UK. I discuss the potential impact of frailty to the older person and financial implications for healthcare providers. I also consider the concept of sense of self-identity and how I intend to define it for this study. I argue that although recognition of and interest in frailty has increased in recent years, understandings of frailty are frequently grounded in social and cultural meanings which are often associated with negative connotations. These socially accepted beliefs will contribute towards how older people living with frailty view themselves and how others view them. I suggest that it is as equally important to acknowledge and understand these beliefs and meanings as it is the physical manifestations of frailty, in order to provide a fully holistic care experience for those living with the condition. Furthermore, I highlight the professional and personal influences that have shaped the concept of the study and the methodological choices made and conclude the chapter with an overview of the thesis.

1.2 Demography of an ageing population

In the UK nearly a fifth of people are over 65 years, and in line with the rest of the world the fastest growth is seen in those aged over 80 years with an estimated 3.2 million people reaching this age by 2041 (Age UK 2019). This changing demographic is often viewed as testament to improvements in healthcare and economy in general (Age UK 2019, David 2014). Living longer can bring with it many opportunities both for individuals and the larger society, older people can gain more time to engage in new activities or pursue alternative careers. Nevertheless, the extent to which a person may feel benefit of this increased life expectancy is often dependent on their health. People are more likely to experience multiple health conditions as their age increases, therefore this increase in life expectancy has also meant that some people are spending more time in poorer health (Office for National Statistics 2018b). ‘Healthy life expectancy’ is the phrase used to describe an estimate of the number of years a person lives in good general health, based on their own perceptions of their health (Office for National Statistics 2018b). Healthy life expectancy in the UK has increased but not as much as life expectancy (Raleigh 2020). This means that although people are living longer, they are experiencing more years in poorer health. Research suggests that the years spent in poorer health has increased for both males and females in the UK (Office for National statistics 2019).

Please see Figure 1 for healthy life expectancy in the UK between 2009 to 2011 and 2016 to 2018.

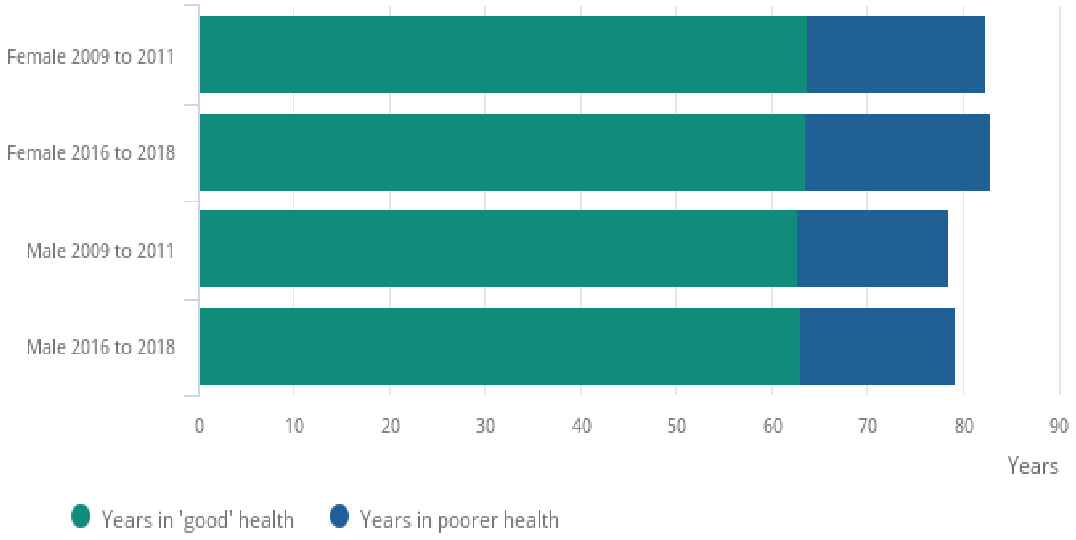

Figure 1: Healthy life expectancy, UK, between 2009 to 2011 and 2016 to 2018

(Office for National Statistics 2019).

1.3 Chronic disease and Frailty

Chronic disease and frailty are two features of ageing that are important modulators of a person’s health trajectory in later life (Weiss 2011). There are several common chronic illnesses associated with ageing such as cardiovascular disease, kidney disease and diabetes (Franceschi 2018), and as people get older the likelihood of developing multiple chronic diseases increases by over 50% (Age UK 2019).

Frailty can be described as a long term condition, the prevalence of which increases with age (Kojima et al. 2019). Not all older people will develop frailty, however those that do are less likely to recover from illnesses and are at greater risk of falls, institutionalisation and death (Kinsella 2018). As the population ages, rates of frailty in the UK are increasing, with half of all people aged over 85 years now estimated to be living with the condition, and this is expected to rise (Clegg et al. 2013; Turner and Clegg 2014). People with long term conditions such as frailty account for most of the healthcare spending in the UK (Department of Health 2012). To support this rapidly changing demographic NHS policymakers and providers need to ensure that they have systems which understand and support the needs of older people with frailty, and which are economically sound. Additionally, these systems should provide the cultural backdrop for individuals to engage with and sustain interventions which may enable healthier ageing and accommodate this increase in ageing and associated health conditions.

In wider society the term ‘frailty’ is commonly used as a descriptor for physical decline in older age. For many, the use of the terms *frail* or *frailty* will engender meanings linked to negative stereotypes of old age and lack of independence, rather than a definitive clinical condition (Richardson et al. 2011; Age UK and British Geriatric Society 2015; Warmoth et al. 2016). It has only been during the last two decades that interest in operationally defining frailty has risen and it is now widely accepted as a distinct clinical syndrome and long-term condition in gerontology (Fried et al. 2001; Rockwood et al. 2015).

1.4 Defining frailty

Definitions of frailty vary, but it is largely accepted that frailty is a dynamic state which develops due to decline in several bodily systems. This results in reduced ability to recover from illness and makes the person vulnerable to relatively minor stressor events such as an infection or a fall (Xue 2011; Clegg et al. 2013; Sezgin et al. 2019). It is a multidimensional health condition specifically associated with aging; however, many clinicians and academics have different ideas of what these ‘dimensions’ are, and this discordance has hindered the acceptance of one clinically operational definition (Clegg et al. 2013; Cesari et al. 2014; Gonzalez-Colaço Harmand et al. 2017).

Frailty has also been operationally defined in several different ways within the literature (Gill et al. 2002; Abellan Van Kan et al. 2009; Romero-Ortuno et al. 2010; Woo et al. 2012). A recent systematic review found nearly half of all selected articles offered their own definition of frailty or a frailty subtype (Roberto Bernabei et al. 2017). Despite this there are two widely accepted diagnostic models that have monopolised clinical practice, the physical phenotype and the cumulative deficit model. The most commonly used physical model is Fried et al’s (2001) frailty phenotype, which operationalises frailty as a syndrome and classifies older adults as frail, pre-frail or non-frail based on them meeting three or more of five physical phenotypic criteria: weight loss, fatigue, activity level, walking speed and grip strength (Fried et al. 2001). While Fried’s assessment criteria shows good construct validity and predictive ability for assessing frailty (Chang and Lin 2015), others have argued it has significant diagnostic limitations as it requires the patient to be relatively fit to perform the physical tests, therefore potentially limiting the number of patients that can be assessed (Bieniek et al. 2016).

Simultaneous to Fried’s work, Rockwood and colleagues worked on the concept that an operational definition of frailty needed to be expanded from a purely physical focus. They presented frailty as a more organic, multidimensional and dynamic creature which required a greater depth of understanding of the non-physiological changes it also encompassed (Rockwood et al. 1998). Considering these non-physical elements in their conceptualisation of frailty they proposed the cumulative deficit model (Mitnitski et al. 2001). This model retains the core physical features of Fried's phenotype model, but additionally measures other 'deficits' that the patient may have such as cognitive impairments, psychological risk factors and common geriatric conditions other than frailty (Rockwood et al. 2005). According to this model the more deficits a person accumulates the more vulnerable to frailty they become. Like Fried's model, the cumulative deficit model has strong predictive validity (Mitnitski et al. 2001), however, in practice clinicians can find the assessment time consuming to complete and therefore it is not practically adopted in many clinical areas. In Table 1. I compare key characteristics of the frailty phenotype and cumulative deficit model.

Table 1: Key characteristics of the frailty phenotype and the cumulative deficit model.

	Frailty phenotype	**Cumulative deficit model**
Diagnostic criteria	Signs, symptoms and Diseases	Activities of daily living and results of a clinical evaluation
Practicality of assessment	Possible to be completed before a medical assessment	Items can only be accumulated after a comprehensive clinical assessment
Categorical measurements	Discrete variables	Continuous variables
Definition	Frailty as a pre-disability syndrome	Frailty as an accumulation of deficits
Ability to perform tests	Usefulness of results potentially restricted to non-disabled older persons	Meaningful results in every individual, independently of functional status or age
Clinical viability	Is quicker than cumulative deficit model but needs equipment	Time consuming to complete

To overcome the problem of the time spent working through the deficits of Rockwood's model, the researchers developed their earlier concepts devising a 7-point Clinical Frailty Scale (CFS) (Rockwood et al. 2005). The Clinical Frailty

Scale (CFS) offers clinicians a quick visual tool to stratify older people according to their level of vulnerability and was found to be highly correlated (r = 0.80) with the Frailty Index (Rockwood et al. 2005) and comparable to the frailty phenotype in identifying frailty without the need for objective resources such as grip strength tools (Cesari et al. 2014). In addition to this it enables clinicians to apply more subjective clinical opinion perhaps posing a more human element to the assessment. For these reasons I have chosen to use a level of frailty as assessed by the CFS as an inclusion criterion for this study. Having briefly touched upon the complexities of defining frailty, I will now discuss how the condition is currently assessed and diagnosed.

1.5 Current context of frailty care in the UK

The concept of frailty as a distinct long-term condition is relatively new in the world of old age medicine in the UK. In 2001 the Department of Health introduced the National Service Framework for older people (NSFOP) (Department of Health 2001). This 10 year programme aimed to provide standardised practice for the care of older people and at the time, was heralded by the Secretary of State for Health as

'the first comprehensive strategy to ensure fair, high quality, integrated health and social care services for older people'. (Department of Health 2001, pg. i).

The framework intended to support independence and health in older people, provide specialist services and embed a culture of dignity and respect; yet a review of its impact in 2004 found that the NSFOP was not widely known outside of health and social care circles and that the experiences and concerns of older people appeared no different in nature to that of non-age specific generalised services (Manthorpe et al. 2007). The National Institute of Health and Clinical Excellence (NICE) has produced guidance and quality standards for what were commonly referred to as 'geriatric syndromes' including: falls (National Institute for Health and Clinical Excellence 2013); incontinence (National Institute for Health and Clinical Excellence 2007); dementia (National Institute for Health and Clinical Excellence 2018). These guidelines approach these syndromes as individual conditions, yet for many older people they may have more than one of these conditions, all of which are elements of a frailty diagnosis. Although one of the aims of this framework was to promote support for complex needs in older people, frailty was still not being fully integrated within national policy agendas.

As little as ten years ago, frailty was still described as an “emerging” concept for general practitioners (De Lepeleire et al 2009), around the same time the first report from the Mid Staffordshire Inquiry was published which highlighted substantial deficits in the provision of care particularly for older people and those with frailty (Francis 2010). Subsequently several policy bodies such as the NHS Confederation, the Local Government Association, Age UK and the Kings fund began to focus on the care of older people and particularly those with frailty. In Cornwell’s (2012) Kings Fund paper she specifically states that frailty is not a diagnosis

“For many older people, however, advancing age is associated with frailty, which is not a diagnosis, but is a useful term that describes the state of ‘limited functional reserve’ or ‘failure to integrate responses in the face of stress,”

(Cornwell 2012 pg.2)

This Highlights that these influential bodies were not using frailty as a diagnosis but as a descriptive term during this time. In 2013 the concluding report of the Mid Staffordshire Inquiry was published which continued to highlight the significant shortfalls in the care of older people including those with frailty. The report identified numerous underperformances including;

- A culture focused on doing the systems’ business – not that of the patients
- An institutional culture which ascribed more weight to positive information about the service than to information capable of implying cause for concern;
- Too great a degree of tolerance of poor standards and of risk to patients;
- A failure of communication between the many agencies to share their knowledge of concerns;

One of the government's responses to this inquiry was to differentiate care and treatment, suggesting that care incorporates people feeling valued and listened to with compassion, and that this was needed in addition to physically treating someone's illness (Department of Health 2014). The inquiry highlighted ways in which health and care services have failed to keep up with demographic shifts and the needs of this increasingly ageing population.

At this point moves towards more complete care for older people with frailty became apparent, with focus moving past the purely physical manifestation of frailty and incorporating more social and psychological aspects of the condition. At a national level this shift was bolstered by the publication of the UK practice guidelines for frailty in 2014, which recommended that a frailty assessment should be carried out at all the encounters between health and social care staff and older people in community and outpatient settings (Turner and Clegg 2014). The two part guidelines Fit for frailty 1 and 2 (Turner and Clegg 2014; British Geriatric Society and The Royal College of General Practitioners 2015) differentiated between older people and those with frailty, rejecting the assumption that frailty is an inevitable part of ageing. Additionally, it recognised the fluctuating nature of frailty and compared it to other long term conditions that are not static in nature. They talk about the need for a holistic medical and multidisciplinary review based on the Comprehensive Geriatric Assessment (CGA) and although many of the assessments remain focused on the physicality of frailty, they do suggest discussion with individuals regarding the impact of the illness. The guidelines were intended to support those managing people with frailty in the community and outpatient settings and looked at the need for recognition of frailty and its subsequent management. The onus was on GPs and other community services to develop care pathways based on these recommendations, however this meant that numerous care models were adopted in different areas further promulgating the fragmentation of support services which were often episodic in nature, reacting to the management of frailty which presented late when older people were in crisis (Kojima et al 2019).

More recently the latest national recommendations for frailty, which recognise the problems of fragmented and unresponsive services for older people, are laid out within the NHS Long term Plan (NHS 2019a). This plan emphases the long term nature of frailty, highlighting the need to establish care models which provide pro-active and continuing support for those living with the condition in the community (NHS 2019a). Focus on early identification of frailty is promoted with impetus on moving beyond the biomedical paradigms to more patient centred care, highlighting and fostering the capabilities and assets older people possess rather than deficits and disabilities, examples of which are discussed in section 1.5.2.

1.5.1 Identifying people with frailty

The dimensions that make up frailty are complex, people who have frailty do not always experience the same symptoms and it is not associated with one specific illness (Buckinx et al. 2015). Frailty is often masked by other chronic conditions and disabilities and this can be challenging as many people with frailty will also have several comorbidities. Frailty can be the inevitable consequence of some chronic conditions in older people such as heart failure or arthritis, but in others frailty itself is the cause of disabilities (Turner and Clegg 2014). It is important to be able to distinguish between frailty and other co-morbidities as disparities can lead to patients being misdiagnosed and not receiving treatment that could potentially support their condition (Fried et al. 2004).

Although the most commonly used clinical definitions of frailty are derived from Central and North America (Fried et al. 2001; Mitnitski et al. 2001), the NHS purports to be the first healthcare system to systematically identify people over aged over 65 years for frailty, utilising a population based stratification approach (NHS England 2020). Since 2017 General Practitioners (GPs) have used the electronic Frailty Index (eFI) to identify people who are at risk of frailty (NHS England 2017). The eFI uses information gathered from primary health care records and a cumulative deficit model to predict a measurement of frailty and is strongly predictive of adverse outcomes in older people (Clegg et al. 2016; Brundle et al. 2019). eFI scoring has also been used in the development and validation of hospital frailty risk scores which may identify people who are at risk of greater adverse outcomes (Gilbert et al 2018).

1.5.2 Assessing, managing and treating frailty

The Comprehensive Geriatric Assessment (CGA) has for several years been accepted as the gold standard to assess, evaluate and manage healthcare for older people including those that have been diagnosed with frailty (Osterweil et al. 2000; Turner and Clegg 2014; Aiping et al. 2017; Nicholson et al. 2017a). The CGA is defined as a multidisciplinary process that identifies holistic needs of older people in order to maximize their potential independence (Stuck et al. 1993; Intiso et al. 2012; Turner and Clegg 2014). It encompasses the systematic assessment of a person by a team of healthcare professionals across a variety of cognitive, physical and psychological domains, and although it is not a diagnostic process, it often includes the evaluation and management of the conditions it identifies. In older people with chronic conditions the goals of diagnosing and treatment are generally different to the models of “treating to cure” (Bouwens 2004). Long term conditions necessitate optimisation of functionality and quality of life, the CGA can be used to collect information in order to structure care and treatment to this effect. However, a full CGA requires a multidisciplinary approach and is time consuming both for the patient and the healthcare team. Consequently, in many clinical environments, a full CGA is considered too cost and labour intensive (Bouwens 2004, Mariano and Min 2012), and therefore derived versions are more commonly utilised in clinical practice.

Although considered a long term condition, frailty can be managed and controlled through appropriate treatment, as many of the individual risk factors for functional decline in older age such as falls, social isolation, poor nutrition, poly pharmacy, anxiety and depression are modifiable (Stuck et al 1999). Most therapeutic interventions to treat frailty are based on improving the biomechanics of the person’s body to improve the physical symptoms. Nearly all treatment programmes have exercise at the core (Gill et al. 2003; Cesari et al. 2015; Kwon et al. 2015). Interventions are provided in a range of settings including inpatients facilities (Nicholson et al. 2017b), at home (Clegg et al. 2014; Walters et al. 2017) and in community outpatient facilities such as Day Hospitals (Ekdahl et al. 2016). It remains unclear where services are best provided for patients with frailty as a recent Cochrane review found no apparent benefit when attending a Day Hospital compared with other comprehensive community services (Brown et al. 2015). Additionally, hospital and community services are predominantly focused on single conditions, with inadequate systems for reimbursement for multiple condition consultations and fragmented support services (David et al 2014).

More holistic ways of managing and treating frailty need to be established, simply characterising people through their health deficits does not adequately consider the complexities of a person's identity or way of being. Several new and existing models of care which are person centred and asset driven (O'Donnell et al 2019, NHS 2014, British Geriatric Society and The Royal College of General Practitioners 2015, Sawicka et al, 2017) are increasingly being discussed and implemented in older persons medicine, many hold common strategies with the management of other long term conditions and include targeted enablement and self -management elements (NICE 2016).

Newer models of care promote earlier identification, prevention, enablement, and self-management as well as better co-ordination of care and transitions between settings (Hendry et al 2018, Vernon 2020). However due to the organisational structure and financial resources of healthcare within the UK there continues to be regional disparities in the implementation and advancement of these models.

Models based on person centred care require the older person to be considered as a partner in their own health care decisions (McCormack 2004). The aim is for care to become more co-ordinated and tailored to an individual's needs, supporting the recognition of people's capabilities and potential to not only manage their own health but also improve it (Coulter and Oldham 2016). These models aim to move away from historically paternalistic healthcare, yet this often requires cultural changes to the way in which health professionals and older people view concepts of health provision (Burd and Hallsworth 2016). Person centred care models have been utilised within the NHS for several years however there is often difficulties integrating and translating them in to practice (Coventry et al. 2015, Moore et al 2017, Thomas and Gray 2018).

Asset based approaches to managing frailty are also increasing (Donnelly 2018, Freer and Wallington 2019, Rahman 2018). These approaches look to maximise personal and social network resources or ‘assets’ to maintain health and wellbeing for older people (Rahman 2018, Wilson and Blandamer 2016), and accentuate an individual’s resources and capabilities (Rahman et al 2018). These models are considered alternatives to deficit approaches which focus on problems, deficiencies, and disease, and instead look to identify and harness resilience and prevention of illness. Asset based models highlight the importance of social interaction, social networks and participation (Daly and Westwood 2017), they focus on the importance of agency and place as well as sense of belonging and community (Rahman and Swaffer 2018). Increases in social prescribing (ways of referring to social non clinical services) has supported these types of asset based models (Buck and Ewbank 2020), nevertheless it may be suggested that this type of approach may be difficult for those living with frailty, as it relies to some extent, on the older person having the physical, mental and economic means to engage in community based interactions and treatments.

It is clear that there is both an impetus and aspiration to improve care for older people with frailty in the UK, but despite the fact that several models of care have been proposed and utilised, evidence of their effectiveness remains insufficient and there is a lack of evidence to support practitioners in the meaningful integration of these models in practice (Lloyd et al 2017).

Having discussed how frailty is currently defined, assessed and treated I now discuss the impact of frailty on both individuals and healthcare services.

1.6 The impact of frailty

For the person living with frailty the impact on their life can be significant. People with frailty often experience chronic fatigue, unintended weight loss and reduced muscle mass. Frailty predicts poor outcomes and functional decline in hospitalised and community based patients (Dent et al. 2013; Gregorevic et al. 2016; Gross et al. 2016). Having frailty has also been associated with poor social functioning and increased loneliness over time (Hoogendijk et al. 2016).

People with frailty are also more likely to experience depression and other psychiatric illnesses (Andrew and Rockwood 2007; Lohman et al. 2016). People with frailty also experience fluctuating ill health which often disrupts their daily lives and can further exacerbate poor mental health, functionality, and isolation (Skilbeck et al. 2018).

In addition to the significant impact frailty has on an individual's life, its complex nature brings additional cost to healthcare providers. There is a paucity of evidence on the current cost of frailty and the cost effectiveness of current interventions. This may be, in part, due to the way in which frailty is often overshadowed by other illness and disabilities (National Institute of Clinical Excellence 2015). Bash and Kerr (2017) presented some preliminary projections based on their on-going study looking at the current and future cost of frailty to Healthcare and highlight the projected increase in GP costs nearly doubling per patient over the next 40 years (see fig 2).

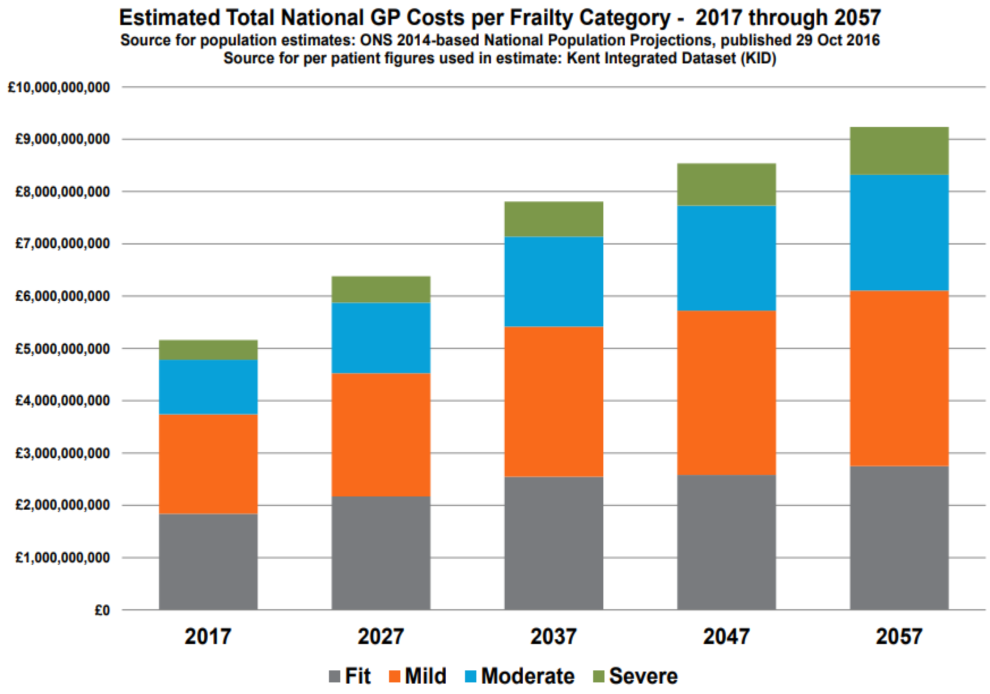

Figure 2 Estimated total national GP costs per frailty category 2017-2057

(Bash and Kerr 2017)

A more recent longitudinal analysis utilising data from the Clinical Practice Research datalink in England found that a person with moderate frailty costs approximately 40% more than a non-frail person within general practice (£1439.37 vs £1021.55). Additionally, they found that admission rates to hospital were over two times higher in those with moderate frailty 2.45 (95% CI: 2.37–2.53) than non-frail older people. Following an emergency admission those with frailty stayed in hospital four times longer (IRR: 4.45; 95% CI: 4.19–4.73) than those without frailty and more than seven times longer if their frailty was severe (IRR: 7.26; 95% CI: 6.61–7.97) (Han, Clegg et al 2019).

Acknowledgement of the potential impact of the condition of frailty has contributed towards clinicians recognising it as a treatable condition; however, perceptions around the condition itself still appear to be grounded within the biomedical model of illness. Many people, including those experiencing the condition, still consider frailty to be irreversible and synonymous with loss of independence, and that it signifies they are entering into the end stage of their life (Lyndon 2015).

Although the costs to finances and resources associated with frailty are high, it is the impact on the person living with the condition which is key from my perspective as a nurse, a researcher and as someone who will hopefully reach older age. As I previously described frailty can have significant impacts on a person's mental health and sense of wellbeing, as clinicians we use the term frail to describe a lack of intrinsic capacity to recover from illness, however the term can be viewed very differently in wider society. Some research indicates that the use of the terms frail and frailty may contribute to a decreased sense of wellbeing for older people, which I will now outline.

1.7 Language of frailty: The 'F' word

The word frail is commonly used in the English language as a descriptor, generally referring to weakness and vulnerability. Searching the dictionary will retrieve other descriptions such as vulnerable, infirm, feeble, incapacitated, wasted, debilitated, crippled, delicate, sickly and decrepit (Stevenson 2010). Because of the negative connotations associated with these words, the language and discourse around the condition can act as a barrier to engaging older people who do not wish to be defined as 'frail' or 'living with frailty' (Age UK and British Geriatric Society 2015). Concepts associated with frailty such as dependency and vulnerability are subjective and culturally constructed through people's understanding of the world, the words themselves, and their lived experience of these concepts (Stephenson et al. 1999b). Therefore, if a person lives in a culture where these words are derogatory or disparaging then it is likely that their understanding of these words will be the same. This is important, as we already know that people experiencing frailty report low levels of wellbeing particularly in relation to their sense of identity and increasing dependency (Andrew et al. 2012). The impact of this can be significant as Twigg and Martin (2015) suggest that a diminishing sense of self-identity in older people can lead to poorer health outcomes and/or reduced engagement in therapeutic interventions.

1.8 Self-Identity in older age

A person’s self-identity is a complex and dynamic concept which has been discussed extensively in the areas of psychology and sociology (Lawler 2014). At its simplest, self-identity can be described as how we know ourselves and make sense of who we are (Burke 2004; Seidler 2009). Self-identity can be constructed from several components, our integrated image of ourselves i.e. definitive characteristics that act and react in a typical way to certain experiences, and how our experiences and associations with society frame our lives (Bailey 2003). It can also incorporate how we view others and define ourselves in comparison, and within, our world (Burke 2004). Throughout our lives we may question who we are on many occasions and our response may change in the present or over time.

I will discuss theoretical perspectives on ageing and identity in greater detail in the following chapter, however I feel it is important to briefly contextualise the lens through which I have viewed identity going into this study. I enter this study with the premise that individuals are shaped by their environment, interactions and societal context. Stryker’s (2001) identity theory suggests that individuals are embodied within social networks from birth which influence their relationships with others and themselves; the society they create is structured by group behaviours and interactions. He theorised that two levels of social structure are apparent, firstly structures around the individual’s identity and their network systems such as their family or work. Secondly he theorised that larger social institutions such as schools and hospitals shape how individuals mix in various networks. For example, in a school environment children are often grouped by academic ability or in a hospital patients are often grouped by their condition i.e. on a cardiac ward or orthopaedic ward. (Stryker and Burke 2000). Stryker and Burke (2000) also suggest that we are able to maintain multiple identities (e.g. self, mother, wife, friend, nurse) simultaneously, and that these identities would present themselves at the forefront at different times depending upon the situation and the level of organisational hierarchy that the person attributed to that identity. So, for example when my daughter was terminally ill, I used my knowledge as a nurse to maintain an understanding of what was happening to her clinically, however my identity as her mother was predominant as I cared for her.

As we age and face different situations our sense of self-identity may begin to change, this may be heightened by loss of functionality and control over physical changes which manifest themselves as part of conditions such as frailty. Older people may ‘gain’ an additional identity of *frail*, with this identity however there is often a heavy focus on the body and physical functionality. The ageing body has been medicalised to such an extent that it appears to be a core feature of that identity (Ebrahim 2002). As the physical body changes there can be an experienced disconnection between the body and sense of self which can lead to a questioned identity. The body which is usually silent comes into daily awareness (Bleeker and Mulderij 1992). This self-body split has been explored and recognised in other health conditions such as stroke where people experience fundamental changes to their identities and disassociations between their functional bodies and their sense of self (Ellis-Hill et al. 2000).

The way in which a culture generates understanding of identities influences how individuals place themselves and others within that culture (Jaspal and Breakwell 2014). Understanding a person’s identity is important in relation to their healthcare as determination of a person’s self-positioning in their world can impact their level of self-worth and potentially their engagement with therapeutic intervention (Holman and Lorig 2000; Hawton et al. 2011; Gershater and Forbes 2013). Burke (2004) highlights that culture defines categories and creates social structures, people adopt roles within these social structures and apply the meaning and expectations associated with the cultural identities to both themselves and others. If we think about the types of meanings socially associated with frailty, we can see that there is potential that people with frailty may identify themselves as weak or useless and subsequently not feel able to engage in rehabilitation.

It is important to understand how having frailty impacts upon a person’s identity and how we as healthcare professionals are contributing to the construction of their social world. We are living in an age where there is a focus on healthy ageing, yet nihilistic associations with frailty may be impeding potential recovery from the condition.

1.9 Professional and personal influence on this research

Throughout my nursing career I have predominantly worked with older people, and have developed an interest to better understand, and a passion to facilitate mechanisms that enable older people to fulfil their potential in later life. The concepts in this study have been influenced by these nursing experiences, my interest in understanding identities, which has been heavily influenced by exploring my personal identity, and a desire for improvement in clinical care.

Since I started my nurse training nearly two decades ago, patients' illnesses have become more complex and multifactorial, yet their hospital stays are significantly shorter. The interaction with healthcare workers is now shorter than ever before yet we are tasked to assess, diagnose, treat, rehabilitate and provide on-going preventative advice. I suggest that never has the need for effective and genuine relationships been greater. When I look at nurses and other healthcare professionals, I see a multitude of personalities, natures and techniques of care. I have worked with many older people and their families in both primary and secondary care and as the years have passed I have come to recognise the importance of a patient's personal narrative in our interactions.

For several years, I worked with older people with long term neurodegenerative conditions. During this role I spent a lot of time in patients' homes, talking to them about their experiences and supporting them with their conditions. Many talked about how their lives had changed yet they "*felt the same on the inside*". It was as if their bodies had become a shell that had disconnected from their being. Living with a long term condition required patients to acknowledge these changes and adapt accordingly but many of these changes were intrinsic to their personal identity. Many became house bound which impacted upon their social life and independence, many became unable to blow dry their hair, put their make up on or dress themselves without assistance. People were experiencing external life changes that impacted heavily on their internal motivations and personas. I also saw this in my own Mum who as she aged really struggled with the changes in her own identity, formed from her appearance and functionality. This certainly impacted her health as for example she refused to use walking aids and therefore had multiple falls and consequential fractures, ultimately developing frailty. It is with these professional and personal experiences that I entered this research journey.

1.10 Overview of thesis

To date, most frailty research has centred on reducing the risk of adverse health outcomes by focusing on physical interventions and measurements of frailty. As a condition, frailty has the potential for treatment and deceleration however to achieve this, recognition of this potential is needed and the development of effective therapeutic relationships within services is essential. Engagement in services can be reduced when they are associated with a sense of a negative or limited identity, as people do not want to connect themselves with perceived limitations. In clinical practice, frailty care is complex because there is still inadequate evidence base for its management at both individual and organisational levels, further research is needed to increase our understanding of which care strategies are effective for frailty. Additionally, it is vital to move beyond the biomedical frameworks and explore and understand how healthcare professionals can support the broader identity needs of older people with frailty when delivering services. This study explores the personal identities of people living with frailty, and how the cultural and organisational processes within an NHS Day Hospital support these. I hope that a greater understanding will enable us to harness ideas to provide us with structured systems of support for the future.

Having outlined some of the core concepts in relation to frailty and identity in chapter 1, chapter 2 provides a narrative review of the current literature on frailty and identity. I argue that although more literature has focused on frailty and identity in recent years, it remains an emerging field. It is also unclear how healthcare professionals, policy makers and the wider society understand, perceive and treat people with frailty; how people with frailty view themselves in terms of the condition and how the culture around frailty supports or inhibits interventions to treat frailty. The lack of clarity regarding these issues means that there is scope to explore how frailty is understood within a healthcare environment that is currently providing such services and how the construction of a frail identity may impact on this.

In chapter 3 I outline the philosophical and methodological foundations for the study, detailing the rationale, relevance and application of ethnographic enquiry in relation to the aims and objectives of the study and my epistemological viewpoint. Furthermore, I discuss the complexities of relationships within ethnography and relate my own positionality and association with the research.

Chapters 4, 5 and 6 detail the specific ethnographic methods used to conduct the study. I set the scene of the study by specifying the study setting, and participants. I describe how the study was planned, taking in to account legal, ethical and methodological considerations. I discuss my role as the research instrument and ways in which data were practically collected, analysed and brought together from the two phases of the study.

In chapters 7, 8 and 9 I present the findings of the study. These chapters reveal the experiences of older people living with frailty, whilst navigating their rehabilitative journey through the Day Hospital. I preface these chapters by providing a reflective narrative of the context within which these findings should be read. Within these chapters we see that older people work hard to balance their sense of self-identity with the physical and psychological effects of frailty and the way in which their identities are impacted by the condition. The findings also present the processes which occur within the Day Hospital that impact upon not only sense of self-identity for patients but also relatives, volunteers and the staff that work there. Thick description of events and interactions are used to give context and comprehension to the data. I present a visual representation of the findings, sections of which I interweave throughout these chapters in order to further illustrate the narrative.

Chapter 10 discusses the findings of this study within the wider literature, whilst Chapter 11 concludes this thesis by demonstrating how this work adds new knowledge and perspectives on our understanding of frailty. I outline the strengths and limitations of the study and detail the implications of the findings for further research and clinical practice.

Chapter 2 Navigating the literature on frailty and identity: insights from a narrative review

2.1 Chapter introduction

In the previous chapter I introduced key areas surrounding the concept of frailty and identity in older age, providing context to the significance of frailty in the current ageing population. In this chapter I will present a narrative review of the literature up to the start of data collection in 2017, pertaining to older people with frailty and their sense of self and identity. Later references will be included in the discussion chapter. This overview enabled me to highlight gaps in the knowledge base and supported the development of the study questions, aims and objectives. In Chapter 1 I discussed that I entered this study with the philosophical premise that there are differing ways to know the world and that individuals are shaped by their environment, interactions and societal context. This perspective and the fact that a preliminary search of the literature highlighted a paucity of literature in the area of frailty and identity, shaped this chapter and my decision to carry out a narrative review.

Much of the general literature looking at the broader psychosocial aspects of frailty, is sociologically rather than medically based and suggests that current understandings around identity and frailty are deeply embedded in historical discourses around frailty and social discourses around ageing. This broader literature highlights how underpinning ageing discourses particularly those of *activity* and *success* continue to influence policy and practice in caring for people with frailty at all levels today. In order to provide some cultural context to this review, it therefore feels pertinent to first briefly discuss these theoretical and societal perspective on ageing prior to the more specific literature around frailty and identity in Section 2.4.

2.1.1 Theoretical perspectives on ageing and identity as underpinning discourses for policy and practice

With a rapidly ageing population there has been increased focus within health and social care literature aimed at supporting older people to live healthier lives for longer. Much of the discourse in this area is dominated by *Active* and *Successful* ageing ideologies, both of which are derived from a similar viewpoint based on the promotion of activity, and have developed through socially dominant theoretical perspectives of ageing (Cumming and Henry 1961; Knapp 1977; Rowe and Kahn 1997), which will be discussed in more detail below. A focus on ageing 'well' has further been fuelled by an increasing emphasis on the financial and systemic burdens to the health service created through the additional demands of a rapidly ageing population. UK parliamentary briefing papers describe the achievements of increased life expectancy during the last century as one of "the great challenges of this one" and suggest that an increasing ageing populace will lead to increased taxation and reduced welfare payments in order to support the population (Ares et al. 2015).

For the last two decades discourses around 'Active ageing' are commonly found in ageing literature and healthcare policy (Department of Health, 2005a; World Health Organisation 2002; World Health Organisation 2015; Boulton-Lewis 2015; Paúl 2012). Since 2011 European ageing polices have focused on increasing healthy life expectancy, and the term 'Healthy Ageing' is now commonly used to incorporate active ageing (Bousquet et al. 2015; World Health Organisation 2015; Illario et al. 2016). However, both concepts are routed in much earlier sociological theory, such as the Activity theory (Knapp 1977). Knapp's (1977) Activity theory ascribes a positive relationship between an older person's level of social interactions, social participation and their well-being. According to this theory older people who actively contribute in societal roles such as participating in social groups, volunteering or membership of organisations will have a higher level of wellbeing and more likely to age well (Diggs 2008).

The Activity theory was proposed in response to an earlier ageing theory relating to disengagement (Cumming and Henry 1961). Disengagement theory proposed that older people purposefully withdrew or disengaged from society as a symbolic preparation for their death (Hollis-Sawyer and Dykema-Engblade 2016). It suggests that there are societal expectations of people entering this life stage where they are contractually, bound through perceived expectation of others, to disengage from certain physical, psychological and social roles, for example employment. In exchange for this disengagement Cumming and Henry (1961) suggested that older people became excused from certain responsibilities and obligations given to younger people, as society reciprocally withdraws from the aging individual. This theory of disengagement was offered to describe the process of 'normal ageing', and as such any older person who failed to disengage from society in this manner was deemed as ageing abnormally, adopting the term of 'unsuccessful disengager' (Cumming and Henry 1961).

Disengagement theory was refuted by many, as the empirical data the theory derived from presented several challenging inconsistencies. Firstly, the data represented a relatively small (n=211) number of participants based in one area of the United States, participants ranged from aged 50-90 years and were deemed ambulatory and healthy (Cumming et al. 1960). Nearly a quarter (22%) of participants remained 'engaged', with over a third (34%) reporting ''high daily interaction with others". The authors however disregard these figures through several counter arguments including referring to these anomalies as those that have been unsuccessful in achieving 'normative' ageing. Additionally, the authors suggested that those who had not disengaged could be described as 'off time disengagers', inferring that disengagement was inevitable and those that haven't yet achieved it will go on to do so. This categorisation of successful or unsuccessful disengagement limited the capacity of older people who did not disengage to be anything other than abnormal or failures, with no acknowledgement that an unsuccessful disengager could simply be classed socially engaged.

Since then, and as life expectancies increased, the concepts of active and successful ageing gained acceptance as more positive propositions than old age simply being preparation for death. More recent health and social care policies regarding active ageing reflect these concepts, which have now emerged as the foremost response to the ageing demographic (Foster and Walker 2015). Activity has been defined not just as the ability to be physically active, but also to actively participate in social, economic and cultural affairs (World Health Organisation, 2002). This perspective challenged cultural labels of dependency and passivity in older age through the promotion of autonomy and social contributions, where older people were given ‘opportunity’ to live their lives as they chose. A predominant feature of this in European policy was through supporting older people to continue to work for longer and feel valued in their roles (European Commission 2009, Walker 2009). However, this somewhat productivist approach towards those around retirement age, negates older people living with health conditions such as frailty where the potential to continue in employment is limited and cognitive and physical losses are much higher (Foster and Walker 2015). Encouragement to continue active employment can also be problematic due to wider social views of older people. Older workers are sometimes perceived to be less flexible, more prone to ill health and less adaptive to change than younger workers (Berger 2009). Working within a culture that hold these perceptions would likely limit an older person's ability to feel accepted and engage in gainful employment (Altman 2015).

The concept of ‘successful ageing’ was adopted by many in gerontology, particularly in the West[1], where culture places high value on the concept of independence, and dependence in older age is often represented and seen as burdensome (Phillipson and Dannefer 2010; Tesch-Römer 2017). Rowe and Khan’s (1997) ‘successful ageing’ is the most referenced model and has been integrated within contemporary health measurements, ageing policy and theoretical paradigms (Katz and Calasanti 2015). Their model proposed a framework within which their idea of *successful ageing* could be differentiated from *usual ageing*, where ageing and illness are distinct processes. This model, based on a biomedical framework, linked measurable indicators of the ageing

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[1] Although I use the terms ‘West’ and ‘East’ within this thesis, I would like to highlight my discomfort with the way these terms are commonly used in cultural reference and the homogeneity they imply. However, I chose to use these terms as they continue to be used and appear to imbue shared cultural tendencies which add context to where this study is geographically situated.

body and disability to physical, cognitive and social factors. In order to age successfully Rowe and Kahn (1997) suggest that older people need to be fully engaged in productive activities and relationships, as well as maintaining physical and mental functioning and preventing disease. Focus is placed on the older persons abilities to retain control over physical exercise, illness and diet in order to optimise functionality.

Successful, *active* and *healthy* ageing paradigms are now commonly accepted as normative frameworks for ageing 'well'. The adoption of these discourses as central features of contemporary health and social care policy and practice, in the UK and worldwide (World Health Organisation 2002; World Health Organisation 2015; Department of Health 2005a; Department of Health 2006; NHS England and Age UK), further promulgates cultural acceptance and sets out a framework for public expectation of ageing.

Activity and engagement are heralded as ways to stave off decline. Yet emphasis on the individual's obligation to maintain these attributes created a cultural discourse where responsibility of health and activity is positioned with the older person themselves. For example, in the NHS England and Age UK (2015) pamphlet, *'A Practical guide to Health Ageing'*, the opening paragraph to the keeping active chapter states:

> *"It can be easy to retreat into the pleasing comfort of an armchair, particularly during the colder months. But taking life too easy can actually speed up the slowing-down process of later life. It's never too late to start being more active or begin an exercise programme. (NHS England and Age UK 2015, g 11)*

This sentence appears to infer that sitting down is a choice rather that a need for some older people, that this choice is perhaps indulgent, through the description *"pleasing comfort*", and that through sitting down the older person is choosing to take *"life too easy*". The autonomy promoted for older people means that health and activity are considered to be choices. If these definitions of active, healthy and successful ageing are compared to the definitions of frailty previously discussed in chapter 1, living with frailty would not equate with any. So where does that leave the person with frailty? The use of such narrow categorisations risks stigmatising older people with frailty as 'unsuccessful' and potentially adding to a diminished sense of self-worth. Older people may feel that if they are not classified as succeeding then they will be worthless (Sjöberg et al. 2017), thus perpetuating the risk of vulnerability they may face and potentially extending feelings of burden and guilt for the older person (Kaufman 1994; Richardson et al. 2011).

Theories defining successful ageing from a biomedical perspective focus on independence, absence of chronic disease and high physical and cognitive function (Bowling and Dieppe 2005). However, the functional focus and parameters in this type of theory homogenises older people in a way that is unrealistic for many with frailty, as physical dependency increases, and social and cognitive function may decline. Often biological and physiological changes occur in frailty which are outside of the control of the individual. The successful ageing paradigm offers little scope to allow for the heterogeneity of illness, ability and choice across this life period and further infers that older people who do not meet the ‘successful’ criteria have somehow failed their ageing process. Furthermore, Rowe and Kahn’s (1997) criteria appear to be disparate from the experiences of older people themselves, for example, in an ageing study where half of older people self-reported aging successfully, fewer than a fifth were considered successful when the successful ageing criteria were applied (Strawbridge et al. 2002).

On paper, active and successful ageing theories are represented as positive solutions to an ageing demographic; in practice however, there is a high risk of idealisation regarding what classifies as active and successful. In Rowe and Kahn’s (1997) model physical and medical achievement is prioritised over social engagement, this leads to a risk, certainly within healthcare, that overemphasis on physical activity is made. Focus on the body and bodily decline in older age could potentially be counterproductive, particularly for people with a long term condition such as frailty. In the UK how an individual should or shouldn’t behave when living with some form of dependency in older age appears to be culturally embedded within societal contexts. For example, negative associations can be created by people who view older people as doing ‘too much’ or ‘too little’ activity, which may impact their levels of dependency (Charmaz 1995). Policy makers and researchers positioning the expectations of activity may do so based on more youthful perspectives, which may be contrasting to the abilities and experiences of older populations (Foster and Walker 2015).

Even if healthcare workers use social engagement as an equal criterion for ‘successful’ ageing, older people with frailty may find engaging in social roles increasingly difficult. Physical changes to functionality may limit or even exclude older people from participating in certain social activities (Goll et al. 2015). The bereavement of spouse and/or friends may also make it harder or less desirable to develop new friendships or social group networks. This theory also does not adequately consider the social heterogeneity of the older population. Some older people may prefer solitary activities or hobbies, this may be influenced by several factors, but personality is likely to be a key contributor to participatory choice, which isn’t considered in the parameters of the successful ageing theory. Financial resources may also be less for older people who have left employment and make it more difficult to participate in social activities.

Another point to consider is the older person’s subjective perceptions of social activity could be as important as the level of social activity itself. From this perspective it is not the level of participation that is necessarily important, more the congruence for the older individual between the desire to be socially engaged and social engagement itself. By proposing ‘objective’ activity both physical and social as the yard stick for good ageing, many older people with frailty are already disadvantaged. It is reasonable to assume that culturally accepted understandings of ageing influence how older people construct their sense of self-identity and rationalise their status in their worlds. Older people with reduced independence due to frailty may further experience feelings of burden, shame, loss of value and disconnection as their physical or cognitive bodies may not enable them to achieve a culturally accepted level of independence (Grenier and Hanley 2007; Gorvin and Brown 2012).

Since these theories were first proposed much has changed in the demographics of older people in the UK, older people who develop frailty are doing so much later in life. The changes in the health and social functioning of this age group was more recently recognised by sociologists who proposed the theoretical perspectives of the third and fourth ages. In direct contrast to

Cumming and Henry's (1961) disengagement theory, Laslett's (1991) conceptual birth of '*The third age'* heralded not only a period of activity and capability but also of positive achievement for older people. Those entering retirement were represented by Laslett as overcoming the stereotypes of old age that earlier theories arguably perpetuated (Silva 2008; Lloyd et al. 2014). Third age theorists attempted to challenge other ageing theories by focusing on diversity and difference of older people (Gilleard and Higgs 2010). As healthy life expectancy increases, older age is more commonly being portrayed as a time of opportunity, activity and learning. Older people leaving fulltime employment are seen as having time to pursue new interests or cultivate new relationships that can increase life satisfaction (Nimrod 2007; Chatzitheochari and Arber 2011). National media advertising in the UK presents this third age as a time to seize opportunities and live a life they choose through travel, cruises and hobbies (O'Grady 2009).

This seemingly positive dialogue surrounding choice and autonomy when entering older age paradoxically infers that those working and in middle age are not enjoying their lives or not living a life of their choosing. For some then, older age becomes a socially more attractive prospect, a time to aim towards rather than shy away from. To participate in this more seductive third age however older people need to fit the ascribed theoretical criteria. Laslett's (1991) "Fresh map of life", suggests that not only do people need the demographic and economic requisites to enter the third age, i.e. financial independence, but also health and vigour. Although several authors have promoted the life possibilities connected to an active third age (Carr 2009; Weiss and Bass 2002), others suggest that this positive, active and leisurely period of retirement is unobtainable for some through economic, ethnic and social disadvantages (Mayer et al. 2001). Those that are financially or physically unable to participate in the activities and hobbies that are defined by the third age criteria find themselves in somewhat of a no-mans-land. Laslett's (1991) requirements do not provide a space for older people with frailty, physical disabilities or economic poverty to socially engage. They are pushed into a different realm, grouped together as failures to achieve the requisites laid out for them, and are commonly referred to as being in the *fourth age* (Twigg 2006; Gilleard and Higgs 2010).

In contrast to the third age, the fourth age is considered to be a life period associated with dependency, frailty and lack of functionality (Lloyd et al. 2014). The promotion of the third age as a positive time in the ageing process has subsequently stigmatised and socially constructed the fourth age when it is considered that those positive opportunities no longer exist for people (Twigg 2006; Gilleard and Higgs 2010). The fourth age is represented within society as a ‘state of being’ rather than a ‘status’, as discourse surrounding it focuses on its economic social impacts, and associated indignities (Higgs and Gilleard 2014). The condition of frailty appears to be well defined by this new old age. Rather than chronology itself, the functionality, contribution and social value attributed to a person by others defines the boundary for entering the fourth age. For Laslett (1991) this fourth age was the inevitable end of the old age, and the start of the dependent period prior to death. Older people with frailty do not fit the criteria for third age membership, regardless of chronological age, actualities of frailty often do not fit within the positive discourses that shape the third age, yet for older people living with frailty this is their lived reality, and many are not simply preparing for death.

It is a confusing situation, not just for older people and their families but also for healthcare workers who provide services. Culturally it is expected that those in the third age should be experiencing life satisfaction (Healy 2004), a concept which is not seen as congruent with the perceived difficulties faced by those in the fourth. Where the third age appears to offer choice and agency regarding growing old, experiencing frailty is seen as lacking the same choices, a time when your physicality and functionality defines your access to options. Lack of clarity around operational definitions of frailty have contributed to this bewildering state, frailty becomes a status attributed to an older person through the perception of others (Gilleard and Higgs 2010). Once a person is perceived to be in the fourth age their level of autonomy is restricted through discourses regarding the costliness of their care or indignities of their functionality. They become the ‘Others’. Focus on independence as an achievement and its contribution to a positive sense of self-identity creates the assumption that those who are more dependent because of their frailty needs are likely to not experience this positive sense of self-identity. Their social positioning and the value that others attribute to their life is perceived to be lesser than before.

Theories of third and fourth ages construct an ageing trajectory where the cross over from one age to another is vague and subjective, based on perceptions of risk and engagement. We are expected to look forward to the ‘freedom’ and ‘autonomy’ bestowed upon us in the third age and simultaneously fear the lack of autonomy, institutionalisation and death that consumes the fourth age (Lloyd et al. 2014). The fourth age does not lend itself to independence, to recovery, there is a sense of inevitability beyond which the process is unknown other than death. Frailty in the fourth age represents dependency, and failure from physical and psychological perspectives.

These theoretical perspectives of ageing have shaped societal views and healthcare practices in the UK. What links all these influential theories is that illness and dependency are not conducive with ageing successfully. Dependency is something to fear, and if the condition of frailty is linked to this dependency then society may come to fear frailty more than death itself (Gilleard and Higgs 2015). Thoughts that when frailty arrives, we are put into a nursing home and abandoned are experienced by many (Lustbader 2008). Frailty becomes a point at which we have failed at being independent. If older people with frailty are attempting to fulfil socially constructed criteria of successful ageing, that for many is unattainable, then there is scope that this will impact a person’s sense of self-identity (Minkler and Fadem 2002). Any of the labels that are attributed to older people such as successful, unsuccessful, disengaged or engaged, negate the heterogeneity of this group of people and maintain ageing stereotypes.

Situated within these theories of ageing is a sense of separation, the good from the bad, engaged from the unengaged the successful from the unsuccessful. Older people with frailty become the ‘Others’, totalised through their dysfunctionality rather than capability. Societal perceptions of ageing are grounded in these theoretical perspectives which have been projected and reflected both academically and through the media. These societal understandings of older age will influence how older people make sense of themselves, their position in the world and ultimately how they construct their identities. Activity is perceived as positive, yet the discourse created can be labelling, inferring lack of activity is bad, a concept which is mirrored in the third age theories. Arguably more detrimental to a person’s sense of self-identity may be the inference, within successful ageing, that the individual is responsible for meeting the outlined criteria. This may create feelings of personal failure for people with frailty who may be unable but not unwilling to achieve this status.

In the next section I will review and outline my perceived influence of these social constructions on the perceptions of ageing and frailty.

2.1.2 Societal response to ageing and sense of self

It is reasonable to assume that the well-established theoretical perspectives on ageing discussed in the previous section of this chapter will contribute to societal views on frailty. Society constructs images, actions, behaviours and language that are associated and expected from older people (Jesuino 2014). Views of aging within a culture will form the foundation of behaviours, systems and customs towards older people (Löckenhoff et al. 2009). Historically, in many Eastern cultures for example, age is associated with wisdom (Fung 2013). Age is imbued as valuable and celebrated, and expectation is placed on the children of older relatives to care for them at home during this life period. These perceptions appear different to those in Western cultures where much greater value is placed on youthfulness and independence (Westerhof and Tulle 2007).

Ageist narratives in the media such as “*grey tsunami*” (Simpson 2014) or “*ageing burden*” (Buckinx et al. 2015) reinforce perceptions of old age as a time of catastrophe and hardship. Some theorise that because of this older people in Western cultures such as the UK will attempt to present themselves as younger during interactions with others in order to increase their sense of social value. This can include their visual image e.g. dying their hair, wearing makeup or having cosmetic surgery to give the appearance of youth, and is grounded in social consumerism which is orientated toward youth, anti-ageing and personal agency (Phillipson and Dannefer 2010; Amatulli et al. 2018). Understanding the role of ageing culture in the UK is crucial to understanding the position that older people face. The youthful or ageing body becomes a marker of identity, which can be significantly influenced by cultural perceptions of accepted body images (Lund and Engelsrud 2008). As bodies visibly age, our perceptions of them can change and so to can the reactions of others towards us (Fillit and Butler 2009). In Chapter 1 I invited you to imagine a world without mirrors, how one knows oneself through one's body, i.e., their mannerisms, gait and appearance, may be challenged by the way in which bodily ageing occurs and the subsequent reaction of others towards that image (Kamps and Berman 2011; Carlson and Kiemele 2016). These perceptions further reinforce the concept that remaining youthful is the individual’s responsibility.

Images representing older people play a significant role in societal perceptions of old age, with images of older age as a period of dependency and decline being prominent throughout the arts and media (Jesuino 2014), reinforcing underlying ageing discourses previously described. Kelly et al. (2016) found that mainly negative representations of ageing were present in 76 popular music texts analysed through qualitative discourse. The study was somewhat limited by the fact that most of the songs were written by younger people, and therefore gives little insight to older people’s perspectives of themselves in this media, however, does highlight prevalent negative representation. Lee et al. (2007) examined television advertisements (n=1977) in the US in order to determine how older adults are portrayed and found that older people appeared in 15% (n=286) of the adverts, within which men appeared much more frequently than women. They also found that adverts with older people were more common in the afternoon compared to the morning or evening (48% vs 21% and 32% respectively). The adverts that older people did appear in tended to be for specific products such as food (24%), medicines (16%), health and beauty (11%) and cars (11%). Older people made infrequent appearances in advertisements for games/toys/fun (1%), beverages (2%), computers/electronics (3%), and holidays/travel (3%), they were not represented at all in advertisements for office supplies/services or sports/sporting gear. These figures suggest that although older people appeared to be represented proportionally to the population, the focus on specific products such as food and healthcare, and avoidance of other linked to fun, computers and travel, propagates categorisations and stereotypes within this age group. Another study which analysed 106 advertising images of older people in UK magazines found that although some advertisements portrayed older people as what they classed “frail and vulnerable”, the vast majority portrayed older people as happy and affluent retirees who were active, and leisure orientated (Kelly et al. 2016). Although these results contrasted with portrayals in popular music, it is somewhat to be expected as the analysis was based on advertising material aiming to sell products or services. Regardless of their probable intention to promote positivity in this age group they reinforce the concept that ‘good’ ageing is only achievable through the ability to be able to travel, participate in activities and be social engaged. This type of imagery perpetuates stereotypes reminiscent of those seen in earlier ageing theories previously discussed and gives little regard to the heterogeneity of older individuals. Those older people who cannot, or do not, want to buy in to the advertised image of ‘happiness’ may experience a lesser sense of self-identity due to these societal perceptions and expectations.

This cultural preoccupation on bodily physicality and activity also imbues the notion that ageing is mainly a biological process, that is therefore medicalised in order to ‘treat’ the ageing body. Individuals are frequently categorised into groups depending on perceived common attributes such as age or health condition, and as a society we generally hold a sense of expectation regarding the behaviour and characteristics of these groups and individuals within them (Lund and Engelsrud 2008). These expectations are common across all age generations for example, we often refer to toddlers experiencing ‘the terrible twos’ and those in middle age may experience ‘a mid-life crisis’ (Williams et al. 2010). However, by categorising people based on our perceptions of them and attributing certain behaviours and expectations of them, we are not allowing for an individual’s life narrative, (their history, experiences and own ideologies) to contribute to their identity. Through categorisation older people are at risk of being stereotyped and discriminated against.

An individual’s sense of self-identity is facilitated largely by their life narrative, historic belief systems, and understanding of their position in the world in relation to the position of others in society. This positionality is structured, in part, through the interaction of the different societal structures including media and everyday life exchanges which collectively shape a person’s identity or expected identity (Hubble and Tew 2013). A dichotomy exists between media advertising and public health representation of ageing. On one hand older people are portrayed by media advertising as having the potential for new opportunities, travel and hobbies (Kelly et al. 2016), yet an alternate portrayal of ageing simultaneously exists where older people are deemed socially and financially burdensome to society. Both representations are reinforced by the media, and health and social care structures (Lund and Engelsrud 2008). Underlying ageing discourses previously discussed in this chapter of activity, participation and disengagement are therefore enacted and reinforced through social representations of older people.

Having given an overview of key theoretical perspectives of ageing and evidence of cultural response to these, I now discuss the more specific literature reviewed regarding frailty and identity, starting with the methods I used to facilitate the review.

2.2 Narrative review: Methods

Narrative reviews comprehensively critique and synthesise previously published literature and information on a particular topic (Green et al. 2006). They can offer more flexibility than more specific systematic review approaches, which enabled me to cast the literature net further, accessing a greater body of works (Allen 2017). This approach also held space to provide a broad but comprehensive view across a range of issues which contribute to the context, theories and dialogue in the area of frailty and identity, and enabled me to critique and summarise the literature in a more exploratory way than other review methods (Green et al. 2006; Coughlan et al. 2013; Baethge et al. 2019). Furthermore, conducting a narrative review facilitated the cross connection of studies where the focus may have been something other than identity in frailty, yet their findings appear to impact and contribute to our understandings of it.

In health research, systems and processes for conducting reviews of quantitative literature are well established and documented (Coughlan et al. 2013; Pope and Mays). Narrative reviews are more commonly associated with qualitative research where the aim is to understand the experiences and perceptions of people rather than testing an intervention (Austin and Sutton 2014). In contrast to systematic reviews there are no universal guidelines for conducting narrative reviews (Ferrari 2015; Pope and Mays 2007), however Baethge et al. (2019) have stated that good narrative reviews should meet six criteria.

1. The topic under discussion is justified
2. The aim of the review is clear
3. Method of literature searching is transparent – (PRISMA flow charts are not required but specifying search terms and types of literature should be included)
4. Essential arguments and key statements should be supported by references
5. Scientific reasoning is made of the studies under review and consideration of their level of evidence i.e. study design etc.
6. Key arguments are supported by appropriately presented data

In order to counter the critique of lack of clarity that narrative reviews have faced (Ferrari 2015; Green et al. 2006), and provide evidence that the literature searches for this narrative review were comprehensive, and increase confidence that the findings and conclusions, I will first outline the way in which I systematically and rigorously searched the literature.

2.3 Developing a search strategy

The area of interest that guided this review concerned the knowledge base, prior to this study, around the sense of self-identity of older people with frailty. I began by identifying keywords and search terms that I felt would yield the most relevant literature. As I searched the literature, I expanded the keywords and search terms. Synonyms and commonly used terms within the literature were added as well as relevant MeSH database headings (Table 2). Truncation operators (*) were also used to ensure that all alternative spellings and endings to words were captured (Butler et al. 2016; Coughlan 2013).

Table 2: Keywords and truncations used during electronic literature search

Older person	Frailty	Identity
Older OR Elder* OR Geriatric* OR Pensioner* OR "over 65 years" OR Age*	Frail* OR infirm OR frail elderly	Identity OR Sense of self OR Self-worth OR "self-worth" OR Self-image OR "self-image" OR Self-confidence OR "self-confidence" OR Belief OR Image OR Well-being OR Wellbeing OR "well-being" OR resilience or "self-esteem" OR self-esteem OR psychology*

Initial searches of the literature identified wide variations of terms used to classify older people and describe identity. Through searching the literature, the terms well-being, confidence and self-worth were often used in association with the word identity and appeared to draw more relevant literature, so these were added to the list. Additionally, self-esteem and self-image were added to the list of key words as these concepts are closely interlinked to identity and appeared to draw in relevant literature.

I conducted a search of multiple electronic databases CINAHL, MEDLINE, PsychINFO, SocINDEX between November 2016 and October 2017. CINAHL, MEDLINE and PsychINFO were chosen as they are commonly considered principle sources for health and social care research and theory (Subirana et al. 2005). SocINDEX was added to provide literature in sociology and related disciplines, and I feel that this enabled me to frame the theoretical perspectives of ageing which appear to have laid the foundations for contemporary perceptions, constructs and policy pertaining to frailty. Additionally, NHS

Evidence was searched using ‘frailty’ as the keyword in order to identify policy documents related to the subject.

2.3.1 Determining exclusion criteria-limiters

The section below highlights the exclusion criteria used to frame the area of literature reviewed. There was a balance between keeping a broad perspective to ensure that relevant literature wasn’t missed and keeping focused so that I wasn’t capturing vast numbers of irrelevant papers (Butler et al. 2016; Aveyard 2014). I iteratively moved through the literature developing the criteria as I explored. I initially limited records to after 1985 and published in English as outlined in Table 3. This initial search strategy produced nearly 6000 articles referencing the keywords used. Reviewing the papers which were deemed most relevant by the databases *(i.e. the first 1500 presented)* there appeared to be significant numbers that concentrated on the experiences of carers and caregivers, which was not the focus of my review. Therefore, I added the Boolean operator (NOT) carers or caregivers which further narrowed the scope for more relevant results. I explored titles and abstracts to determine the relevance of the papers excluding those that did not relate directly to identity and those that related to older people living in institutional care. For papers where I was unsure of relevance, I read the full text making notes of key findings, strengths and limitations.

Once I had reduced the literature to a manageable amount of full text papers it was clear that there was a paucity of primary source studies in this area. In order to ensure that as much literature as possible was considered I also hand searched the reference list of the full text papers to capture literature which did not appear through the database searches. Additionally, I further carried out a more generic search via google scholar to attain any additional literature that may not have previously been highlighted.

Table 3: Exclusion criteria and justification

Exclusion Criteria	**Justification**
Records prior to 1985	The concept of frailty as a clinical condition was first proposed in the late 1980s, preliminary searches prior to this date produced little relevant literature
Not published in the English Language	Due to limited resources, studies published in languages other than English are unable to be translated and included into the review.
Papers that focus on Carers of people with frailty,	Expanded the population focus too broadly
• Papers focusing only on defining frailty • those that focused on frailty as a predictor for outcomes in illness • papers that focused on frailty in relation to a specific condition (such as cancer) or surgery • the biomechanics of measuring or treating the condition such as those focusing on gait measurements or grip strength	No reference to identity
Papers relating to older people living in institutional or assisted living settings	The focus for the review was older people living in the community rather than institutional settings

2.3.2 Synthesizing qualitative evidence

The systematic synthesis of data is often associated with positivism, and the notion that the gathering and synthesis of research findings will reach a single ‘truth’ (Pope et al. 2007). As a qualitative researcher I do not adopt such a positivist outlook and as such the findings of these different research studies (Table 4) are viewed as providing distinct and unique views of reality, with differing methods eliciting multiple truths. Whilst I recognised the benefit and need to build an interwoven knowledge base within the subject, I was also aware that individual studies hold a contextual richness which needed to be acknowledged and appreciated.

Once the papers for the review were gathered via the exclusion process detailed in Section 2.3.1, the papers were individually critiqued adapting elements of the Critical Appraisal Skills Programme (CASP 2016) tool and Spencer, Ritchie et al. (2003) Quality Appraisal Framework as supporting guides to identify the methodological strengths, credibility and limitations of the evidence. The CASP tool was chosen as it is one of the most used appraisal tools for qualitative evidence synthesis and covers a broader spectrum of methods than other tools such as COREQ (Tong et al. 2007; CASP 2016; Majid and Vanstone 2018). I also referred to the Quality Appraisal Framework (Spencer et al. 2003) as found this to provide more in-depth analytical points to consider. This information was then collated in table form (Table 4), in order to easily compare literature for synthesis. I read and reread the papers analysing their findings and conclusions, I began to iteratively synthesise the papers, identifying areas of similarity or disparity and gaps in the literature. The aim of the review was to broadly understand what is known in the area under consideration (Holloway and Galvin 2017), and to identify gaps in this body of knowledge. After the areas for the review were identified additional literature was sourced from the same electronic databases in order to reference my synthesis and provide robust background and context to the key areas of interest that emerged.

Table 4: Specific identity and frailty studies

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
1. Taylor, B. 1992 USA	To understand the conversational development of intergenerational relationships and to increase understanding of older people from their own perspective.	Participant observation and intensive interviewing of 3 older people living with 4 younger college students who supported them in exchange for rent in their own homes. Observations and interviews were conducted over a 6-week period once a week for 1-2-hour period.	The negotiation of frail elderly identity emerged as a central dimension of the interaction between the older person and student. Frailty is one frame through which the identities of older people may be defined. It is one mode of being in the world accomplished through discourse.	The use of an interview techniques which increased and encouraged reflexivity of relational partners regarding their involvement with each other. Interviews were audiotaped Recognition of the philosophical stance when analysing the data.	Study is nearly 30 years old All the participants were white and members of a specific religion (Mormons) which may affect the relationships, and lived experiences, and which reduces the generalisability The original data was gathered by the author in 1985. This is very early in the concept of frailty and the cultural understanding that surround it, as well as the understandings generally of older people and identities have changed.	Identity can be assembled, displayed and negotiated through conversation. Self-identity can change and frailty is one mode through which older people may identify. Interpersonal strategies may help or hinder the tension that frailty produces in relationships with older people. Older people sometimes use frailty to elicit praise and sympathy, fight negative stereotypes and to ameliorate themselves from roles. In this way the production of frailty may be beneficial, but also disempowering for older people.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
					Sample was purposefully chosen via the homeowner program coordinators' subjective opinion of those who would be unwilling or unable to participate. The visits were limited over a 6-week period, with a maximum of 12 hours per household of observation.	
2. Kaufman, S. 1994 USA	Investigate ways in which frailty is defined, framed, and understood by older persons, their family members, and their health care providers in the context of a multidisciplinary geriatric assessment service.	Anthropological observations of 43 Community dwelling people over the age of 80, who were perceived to be at risk by family members or health care professionals during their comprehensive	Frailty is socially produced in response to cultural discourses about surveillance and individualism. Subjective experience is interpreted in a medical/social service idiom. Lived experience is transformed during the medical encounter into a	One of the earliest explorations regarding how people understand frailty. Large sample size for this method Included people with severe cognitive impairment	This study is now over 25 years old. Recruitment focused on people who were brought to healthcare professionals by others and unclear how people were consented to study particularly those with cognitive impairment.	Identification of the battle between medicalisation and autonomy paradigms in healthcare, particularly in the area of older people.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
	Study rationale well supported by context to current climate and previous investigations.	geriatric assessment in a healthcare clinic. In addition to the 43 cases, 25 family conferences were observed and 10 interviews with the older person or their family member.	problem list that encompasses personal and social behaviours as well as physiological disorders. No one party is solely responsible for the transformation.	Participants had a broad spectrum of functionality Gives descriptions of cases to support findings Findings and conclusions well supported by study data	Based in USA with a very different health system to UK	
3. Coleman, P, Ivani-Chalian, C, Robinson, M. 1999 UK	To validate two theories of identity in old age. One focusing on management of self-esteem, the other on development of identity as story.	5 Case studies drawn from a 20-year longitudinal study of aging The Southampton Ageing Project) which began in 1977 were examined for the support they provide to two theoretical viewpoints on the Self in later life.	The two theoretical viewpoints complemented one another but the findings did not provide strong support to distinctions between earlier and later old age, continuity was more evident than discontinuity. Management of self and development of identity is through life stories.	Longitudinal case studies offer a depth of information when developing theories over time. Case studies well explained Quotations and examples used to facilitate findings	Although there are benefits to the use of longitudinal studies in ageing, the people that were able and willing to be interviewed may not be representative of the original population. Process of analyzing and synthesizing the data was not well explained	The evidence from intensive study of these five cases runs counter to the view that story making declines in importance in advanced old age. Story continues to be used not only in making sense of the past, but interpreting the present as well

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
		Participants were chosen from survivors of the original study between 1977 and 1980 and interviewed on 4 separate occasions at 2/3 yearly intervals between 1990-1998, in addition to the interviews they also carried out some of the original psychosocial and clinical measures.		Based in UK, representative of people experiencing UK healthcare system. Acknowledgement of relationships between research team and participants and how the development of that over time may impact results. Methods well explained. Case study data appropriately provided in context		
4. Grenier, A 2006	To explore older women’s narratives regarding frailty and	Narrative interviews regarding the concept of frailty	She suggests that older women's identities and strategies are negotiated in	In depth interviews	Not clearly explained how the women were defined as frail or not	Adds understanding of frailty by moving from the biomedical concept of

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
Canada	the lived experiences of older women.	conducted with 12 diverse older women.	relation to the experience of 'feeling' frail, that the identity and self may serve as a protective mechanism from 'becoming' frail, and the existence of a threshold between these two conditions. Women rejected concepts related to decline and dependency Women experienced a body/self-tension where changes in the body threatened the 'self' Encounters within health and social care require modification to included consideration of emotional experiences.	providing rich data source Well justified choice of methods Uses example quotes from the interviews to support findings. Context of data sources well retained and portrayed.	frail and how many were in each group. No clear explanation of how and where the interviews were conducted other than in Quebec. Says that the women are diverse but doesn't explain in what sense and how this is categorised. All participants were women and although this gives good insight into women's understanding there is scope to understand men's views.	frailty into the emotional aspects that lie within the experiences of impairment, disability and decline in later life Differentiates between being frail and feeling frail
5. Lund, A. Engelsrud, G. 2008	To examine older people's attitudes towards their own ageing and towards others who are older	Participant observation of users of a seniors' center in Norway.	Participants held 2 sets of attitudes. They saw the center as helping them thrive and	Clear explanation and reasoning of why study site was chosen.	With ethnographies the data is co-constructed through the researcher and	Distancing strategies used by users of the center further supports the value of youthfulness

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
Norway	and frailer than themselves.	100 hours of data collection over 3 months.	partake in community activities which created a sense of belonging. Some perceived the center and other older people there as threats, reminding them that they were getting old and increasingly vulnerable. They in turn distanced themselves from others.	Researcher relationship explained Data was analysed as gathered and explanation of process given. Terms close to the participants vocabulary were used as theme headings Context of data was maintained	this needs to be acknowledged.	and negative representation of old age.
6. Nicholson, C, Meyer, J., Flately, M, Holman, C, Lowton, K. 2012 UK	The aim of the study was to understand the experience of home-dwelling older people living with frailty over time.	Combined psychosocial method. Data collection and analysis takes account of emotions felt as well as words spoken. Up to 4 Interviews conducted in home	Three main themes arose from analysis. *The dynamics of physical and psychosocial frailty*: the persistent state of uncertainty and loss experienced as a result of progressive physical and psychosocial changes.	Interviews conducted overtime allowed for deep understanding of the experiences. Temporality of felt experience was considered and incorporated into the analysis.	Methods used have been criticized for focusing interpretation to heavily on people and ignoring larger cultural structures which may be shaping and influencing experiences.	This study argues that frailty in later life is a state of imbalance in which people experience loss of both physical and psychosocial connections. Yet frail elders work actively to retain anchorage in this state of imbalance through developing and sustaining

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
		over course of 17 months. Frail older people were identified through an older persons' intermediate care team comprising community nurses, speech therapists, physiotherapists, occupational therapists, care support workers and a geriatrician. 17 participants aged 86-102. 5 men and 12 women, all living in home environment in the community.	*Sustaining connections within the home:* older people work to remain anchored within the imbalances of their frailty. *Connecting with death and dying:* addresses older people's work of acknowledging and communicating finitude within frailty.	Participant were much older in age than some studies which may add additional dynamic to frailty that others could to achieve through their population. Reasonable sample size, mix of genders being commonly reflected in other studies male/female ratios	Participants were recruited from healthcare service teams and therefore may have developed differing experiences than those who do not interact with health services.	connections to their physical environment, routines and social networks. No participants used the term frail to describe themselves or their situation.
7. Andrew, M. Fisk, K. J. D and Rockwood, K.	Investigating associations between well-being, frailty, and mortality in community-	Secondary analysis of the Canadian Study of Health and Aging (N = 5,703; age 70+).	For each additional frailty-defining deficit, the psychological well-being score worsened by 0.3 points independent of age,	Large sample size Large data sets looking covering multiple aspects of the participant.	Secondary analysis means that there is potential for incomplete information and data can be gathered for	Frailty was associated with low levels of well-being. Psychological well-being impaired by a frailty

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
Canada	dwelling older Canadians.	Frailty was defined by an index of 33 health deficits. Psychological well-being was measured using Ryff's 18-item scale, with six domains	sex, education, cognition, and mental health. Worse psychological well-being was associated with five-year mortality independent of age, sex, education, frailty, and mental health; this association was not statistically significant when adjusting for baseline cognition.		other reasons that may not always be conducive to the question.	identity crisis may play an important role in defining subjective health in older adults.
8. Horder, H, Frandin, K, Larsson, M 2013 Sweden.	To explore successful ageing from the perspective of community-dwelling older people.	24 persons aged 77–90 years participated from a small urban community in western Sweden. 9 female and 15 males. Individual open interviews were conducted and analysed according to qualitative content analysis.	An overarching theme was formulated as "self-respect through ability to keep fear of frailty at a distance". And that this was important for successful ageing. This was achieved either by continuing to actively take part in the outside world or by trying to keep ones' mind from focusing on oneself and one's own vulnerability. With four subcategories.	Qualitative content analysis can identify similarities and differences in text which may apply to participant's variations in their experiences of successful ageing. More male participants than in other studies	Participants were recruited from an RCT that they had been involved in. 18 of the participants were in the original intervention group of the first study, although they included 6 from the control group of the original study to help minimise bias, the potential is there. The authors do	Ageing is a dynamic process rather than a static structure and might therefore be susceptible to actions. Paying attention to attitudes and treating the older person with respect, particularly regarding worries about increasing vulnerability, can lead to better ways of promoting successful ageing.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
			1. "having sufficient bodily resources for security and opportunities", 2. "structures that promote security and opportunities", 3. "feeling valuable in relation to the outside world", 4. "Choosing gratitude instead of worries". Ageing is a dynamic process which may be susceptible to actions.	Clear description of participants demographics Authors addressed issues around trustworthiness, credibility and transferability and detailed how they managed these.	recognise that this led to a more homogenized sample and more positive attitude towards health and ageing. One of the exclusion criteria was that no home care services were needed so perhaps the level of frailty was lesser than in other studies. Interview times varied from 12-70mins which suggests that the greatest contribution to the data came from those that could articulate well.	
9. Ipsos MORI 2014	To explore the lives of older people with different degrees of frailty and consider	5 filmed ethnographic interviews followed by 3 visits to older	Five themes were developed from the data. - Acknowledging frailty	Data collection is appropriately explained and rationalised well.	Relatively small-scale study, potentially limiting findings.	Frailty appears to be easier to see in others than accept in one's self.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
UK	factors that could have a positive impact on their lives.	people's day centers where informal focus groups and in-depth interviews were conducted. 5 follow up in depth interviews were also conducted with participants who agreed to be contacted from the day center.	- Independence and control - Support and assets - Loneliness and isolation - Adaption to life changes.	Participants were summarised as case studies within the report. Quotes are used to support findings Participants were recruited nationwide minimizing regional bias.	Unclear as to how participants were recruited and through which channels.	Differences exist between what health care professionals define and frail and the perception of frailty by the people defined to have it. Older people who received some form of support appeared more independent than those that did not. The diversity of responses in the group highlights how intervention and services should be personalised as much as possible.
10. Gale, C. R., Cooper, C., Deary, I. Sayer, A. 2014	To examine the prospective relation between psychological wellbeing and incidence of physical frailty or pre-frailty.	Multinomial logistic regression in 2557 men and women aged 60 to over 90 years from the English Longitudinal Study of Ageing.	Men and women with higher levels of psychological wellbeing were less likely to become frail over the 4-year follow-up period There was a significant association between psychological wellbeing and risk of pre-frailty	Large sample size Sample taken from wide demographic area in UK. Participants had rigorous measures taken to define frailty via	Only 14% of participants were classed as frail. Unable to assess if psychological wellbeing assessed prior to the development of frailty might promote	Maintaining a stronger sense of psychological wellbeing in later life may protect against the development of physical frailty. Future research needs to establish the mechanisms underlying these findings.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
UK			Incidence of pre-frailty or frailty was associated with a decline in wellbeing, suggesting that the relationship is bi-directional. Maintaining a stronger sense of psychological well-being in later life may protect against the development of physical frailty.	both physical measurements and validated questionnaires. Inclusion of data on blood inflammatory markers which are known to influence lower levels of wellbeing.	transition to a less frail state. Not all participants gave blood samples and those that didn't tended to be older and in poorer health. Quantitative data may not reflect personal lived experience	
11. Age UK and British Geriatric Society 2015 UK	To gain insights into the lives of older people with and without frailty and views of healthcare professionals in order to prevent or minimise the impact of frailty.	Focus groups and individual interviews October and November 2014. **Focus groups** Two single sex focus groups of older people without frailty one in South and one in North, plus 1 x FG with informal carers of group in South	Older people did not identify with the term frail and do not use the word in their day to day living. People are fearful of frailty as they relate it to losing independence and nearing end of life. Older people's experience of living with frailty is defined by several specific challenges.	Conducting research in two centers gives greater variation of participant and regional bias potentially reduced. Accessibility issues were considered for participants to attend interviews	The small sample sizes mean that the full scope of audience experience and opinion may not be represented. No older people living in care homes or sheltered accommodation were consulted as part of this research, nor were any older people with a frailty score above 8, as	Frailty as a clinical concept has a different meaning amongst the general public and non-old age health professionals. It is possible to position the concept of frailty in such a way as to encourage older people to identify with it by using specific examples of living with frailty in order to drive self-identification.

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
		n= 5. Sessions lasted 75-90 mins **Individual interviews** Interviews with older people with frailty in their lasting 60 mins. n= 7 in Manchester (North) and n= 5 in Southampton (South). 1 x interview with Hospital ward manager in both North and South lasting 75 minutes 4 practice/district nurse telephone interviews in North and South lasting 40 minutes 2 non specialist HCPs telephone interviews in North		Multiple data collection techniques provide robustness to findings Specific quotes were used to support findings Examples of interview questions used.	measured on the Rockwood Frailty Scale.	Using language that resonates with older people's desire to maintain or return to a level of independent living will be beneficial for rehabilitative intervention.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
		and South lasting 40 minutes				
12. Taube E, Jakobsson, U, Midlöv, P, Kristensson, J. 2016 Sweden	To explore the experiences of loneliness among frail older people living at home.	12 participants were purposively selected from a larger interventional study conducted in a municipality in Southern Sweden. The aim of the interventional study was to evaluate case management for people aged 65+ years with dependency for activities of daily living (ADL) and repeated contacts with healthcare services (performed single, semi-structured, one-to-one interviews were conducted with each of the participants in their	The analysis resulted in the overall theme 'Being in a Bubble', which illustrates an experience of living in an ongoing world, but excluded because of the participants' social surroundings and the impossibility to regain losses Three key themes were identified 1. *Barriers:* was interpreted as facing physical, psychological and social barriers for overcoming loneliness. 2. *Hopelessness:* reveals the experience when failing in overcoming these barriers, including seeing loneliness as a constant state.	The interviewer was not clinically involved in the participants' care and therefore could take a more objective standpoint. To enhance variations in data, participants were chosen that reported differing levels of loneliness. Researchers noted previous experience in interviewing and described questioning type and interview Notes were analysed	Participants were selected as all had expressed feelings of loneliness and no comparative control. Genders of participants were outweighed 10 women to 2 men.	Discrepancies identified between what frail older people receive or are offered in terms of support strategies for loneliness and what they require. Future strategies for older people with frailty should target individual barriers and promote positive co-existing dimensions of loneliness. Person centered approaches including physical and psychological aspects of frailty such as loneliness is recommended.

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
		homes, with no one else present. The interviews were conducted from December 2009–August 2011 and lasted from 47-119 minutes. And qualitative content analysis was used to analyse data.	3. Freedom: A positive co-existing dimension of loneliness, offering independence. The findings suggest that future strategies for intervening should target the frail older persons' individual barriers and promoting the positive co-existing dimension of loneliness.	alongside reflective summaries and coded literately with other researchers. COREQ3 guide was used to support explicit reporting. Demographics of participants were described. Selected quotations were used to substantiate findings and examples of coding and analysis were present in the paper.		

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
13. Warmoth, K., Lang, I. A. Phoenix, C. Abraham, C. Andrew, M. Hubbard, R. Tarrant, M. 2016 UK	To explore older people's perceptions of frailty and their beliefs concerning its progression and health consequences.	Grounded theory In depth interviews with 29 people, males (n=12) and females (n=17), aged 66-98 with varying degrees of frailty. Purposive sampling (early phase) Theoretical sampling (later phase). Semi structured interviews conducted in participant's homes or private room at university. Topic guide used to direct interviews and key themes health, daily life, experiences of getting older and participants	Older adults in this study described frailty as a negative physical and psychological condition. The adoption of a frailty identity depended on resistance strategies and aspects of self-identifying. The process and strategies were informed by both individual and social context. The conceptualisation of frailty varied between older adults and differed from that used in clinical contexts.	In depth interviews providing rich qualitative data regarding the views of frail older people in the UK. Sample recruited via variety a number of community organisations from community dwellers and those living in care homes. Reasonable sample size and mix of genders Recruitment was modified part way through the study due to early participants being healthy and young, ended up with broader	Sample was recruited from a single area in South west of England. Recruitment occurred through community organisations where people were already engaging in social situations therefore the demographic was narrow, and participants may have had more positive outlooks on life. Nearly all the participants, although retired, would be classed as professionals. Used a self-reporting questionnaire to total deficits then indexed against clinical frailty scale (this may not be very accurate	Being labelled by others as 'old and frail' contributed to the development of a frailty identity by encouraging attitudinal and behavioural confirmation of it, including a loss of interest in participating in social and physical activities, poor physical health and increased stigmatisation.

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
		understanding of frailty.		sample after this modification. Clear explanation of how data was collected Lay findings were summarised and sent to recruiting organisations and received positive and confirmatory comments Uses example quotes from the interviews to support findings. Data collection and analysis were performed iteratively so themes and concepts could be revised as study progressed.	bearing in mind the result that people tend to distance themselves from these deficits.	

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
14. Skilbeck, J, Arthur, A, Jane Seymour, J. 2018 UK	To explore how older people with complex health problems experience frailty in their daily lives.	An ethnographic study of older people, living at home, receiving support from a community matron service in a large city in the North of England Up to 6 care encounters with each of 10 older people, and their community matron, were observed at monthly intervals, over a period ranging from 4 to 11 months. Semi-structured interviews were conducted with the older participants in their own homes. Fieldwork took place over a 4-year period.	Frail older people experience episodic moments of frailty in their daily lives where daily living becomes precarious. Frail older people work hard to shape and maintain daily routines in the context of complicated and enduring transitions in health and illness. Experience of frailty is understood through the construction of 4 themes. - Fluctuation of ill health and disruption of daily living - Change in the management of daily living - Frailty as anxiety and uncertainty - Making sense of changes to daily living	Clearly explained recruitment and selection criteria and process. Differing data sources were analysed in context with each other, facilitating detailed exploration of contributing factors. Appropriate use of quotations and description used to support study findings Ethnography is an appropriate methodology to explore experience in daily lives. Data collection process clearly explained, and	Access to participants were through the community matron team which may have created some bias in sample. (however, author does reflect upon this) The community matrons subjectively determined the presence of frailty; an objective measurement would have enhanced the recruitment of frail older people. No participants were included who had difficulty communication through illness such as dementia or stroke so findings cannot be	When planning personalised care for frail older people their experience of fluctuating ill-health must be explored. Health professionals should look for opportunities to enhance the coping strategies of frail older people by focusing on situations that challenge their resilience. Policymakers need to consider how frail older people manage their experience of fluctuating health and enduring transitions. Further longitudinal research, rather than a cross-sectional approach, is required to explore how nurses can utilise the personal experience of

Author, Year and Country	Aim of study	Method, setting and participants	Key findings and credibility	Strengths	Weaknesses	Contribution to knowledge/ practice
		Data analysis was undertaken using the constant comparative method.		examples of interview questions given in paper. Equal weighting was given to observational and interview data. Credibility, dependability and transferability were considered and explained.	generalized to include this group. Potential bias due to researcher's positionality although this was reflected upon and considered.	frailty in assessment and care planning. The findings highlight the knowledge, skills and attitudes that nurses require to care for frail older people.
15. Nicholson, S. Gordon, A. Tinker, A. 2017 UK	Commentary paper discussing the perception of frailty by different key stakeholders – most notably older people.	Commentary paper	There is antipathy to the term frailty from older people, from non-specialist clinicians and from policy makers. Frailty is a negative label given to others who are seen to be more unwell than themselves. Older people do however recognize their own vulnerabilities. Frailty is associated with giving up and not something to identify with.	Authors are experienced and well regarded in the field. Reference other papers appropriately in the field.	Commentary paper, not empirical study will potentially hold more bias based on authors personal opinions.	Suggest integrating predominantly medical driven understanding of frailty within a wider conceptual framework. CGA should only be part of the frailty process and focus should move away from limitations and restrictions.

Author, Year and Country	**Aim of study**	**Method, setting and participants**	**Key findings and credibility**	**Strengths**	**Weaknesses**	**Contribution to knowledge/ practice**
			Frailty is an insufficient concept to base all discussions about ageing and functional decline.			Engage in dialogue that is more inclusive and meaningful.

2.4 Specific literature around frailty and identity

Exploring the literature, I found a paucity of empirical studies that specifically focused on identity in older people with frailty. There were only 12 empirical studies that were felt to meet the search/exclusion criteria, one further empirical study I felt contributed insights to identity, although its study focus was loneliness (Taube et al. 2016), and a commentary paper which I felt held significant relevance to the construct of frail identities (Nicholson et al. 2017). Additionally, I included one paper from a longitudinal study based in the UK which looked to validate two existing theories of old age (Coleman et al. 2001), as I felt both their data and findings contributed to the discussion of identity in later life. Those that highlighted understandings in this area were generally aimed at exploring the lived experience of frailty, where reference to identity and sense of self was made (Coleman et al. 2001; Grenier 2006; Nicholson et al. 2012; Warmoth et al. 2016; Skilbeck et al. 2018)

2.4.1 Overview of specific literature

Interest in exploring the construction of identity in older people with frailty appears to have begun in the early 1990s in the USA within the field of sociology. These early observational studies Taylor (1992) and Kaufman (1994) focused on the construction of identity through societal understandings of frailty and power relationships. As interest in the concept of frailty as a medical condition began to increase, much of the literature focused on establishing operational definitions of the condition and little appears to be written about the relationship of frailty to a person’s sense of self-identity. Interest in understanding the experience of frailty, and how it is cognised by older people has however gained some momentum in the UK within the last 10 years. This appears to coincide with increased acceptance of operational definitions of frailty within the health system. In most studies reviewed, participants were accessed through health or social care services and methods used across much of the identified literature are similar, observations and individual interviews being the most popular data collection techniques. There is a sense of realisation over time within the literature that older people have a voice. In comparison to the early studies such as Kaufman's (1994) where the focus of care for the older person was almost carried out around them, often precipitated by their families, later studies in the UK such as Warmoth (2016), Nicholson (2012) and Skilbeck (2018) hold much greater focus on the older individual and their opinion of their lives.

Three key characteristics were apparent from reviewing the literature in this area. Firstly, the condition of frailty continues to be predominantly viewed, assessed and treated through a biomedical lens. This creates a disparity between service users and providers conceptualisations of frailty, which are shown to generally differ between old age clinicians and older people themselves (Warmoth et al. 2016). This medicalisation of frailty can generate increased complexity for those living with frailty as they navigate effects on autonomy, identity and self-determination. Secondly, older people with and without frailty attach negative connotations to the term itself (Grenier 2006; Horder et al. 2013; Age UK and British Geriatric Society 2015; Warmoth et al. 2016), those clinically defined as frail often do not see or describe themselves as frail (Nicholson et al. 2012; Ipsos MORI 2014; Age UK and British Geriatric Society 2015; Warmoth et al. 2016). Because of the negative connotations associated with frailty older people with and without frailty actively distance themselves and resist being classed as frail both in physical and social situations (Grenier 2006; Horder et al. 2013; Warmoth et al. 2016). Finally, the literature suggests that many older people appear to work hard to 'fight' their frailty diagnosis and use strategies to maintain their identities within this biomedical framework (Skilbeck et al. 218, Nicholson et al. 2012).

A joining thread throughout much of the literature is that people whether healthcare professionals, older people or others have their own perceptions of what frailty means. As described in chapter 1, debates regarding the operational definitions of frailty constitute much of the literature in this area. The current use of frailty phenotypes enables clinicians to objectively define frailty in ways that can support therapy, however Whitson et al. (2007) highlight the challenges faced by many older people regarding the terminology and discourse when labelled with frailty. Purely conceptualising frailty through the limits of physiological functioning can lead to disparity between what a clinician views as clinically frailty and what the older person is experiencing. Although limited in number, the qualitative studies in this area show acknowledgement by older people that they experience some of the conditions associated with frailty such as fatigue and falls, however their lived experiences of these conditions does not automatically equate to the label of frailty for the older person (Grenier 2006; Age UK and British Geriatric Society 2015; Warmoth et al. 2016). Their lived experience has been medicalised which leads into the negative discourse, stereotypes and perceptions which I have previously discussed. From a healthcare perspective, the only option in response to this medicalisation appears to be a medically driven one. This outlook may limit the potential to fully support a positive sense of self-identity for people living with frailty.

2.4.2 The medicalisation of frailty

One of the earliest qualitative studies to link the construction of frail identities to social perceptions and the biomedical model was Kaufman (1994). Kaufman (1994) looked to understand social-cultural dimensions of frailty in an American Geriatric assessment unit. She used ethnographic observations of 43 multidisciplinary conferences, 25 family conferences and interviewed 10 older people with frailty and their families. She argues that frailty was socially constructed within the healthcare encounter, lists of problems were articulated within clinical consultations and at this point the older person became a ‘patient’. These problems were viewed through a biomedical lens and the older person’s lived experience was transformed into diagnoses and treatments. The treatments were often seen as the solution to the problems identified, however they were constrained within medical and social parameters and services. During her observations Kaufman (1994) found that these ‘solutions’ became the focus of each of the cases and were seen by the healthcare team as the way to preserve the person’s independence and autonomy, however the older persons autonomy was itself constrained by the healthcare team as it could only be enacted within the structure that they could provide. The lived experience of frailty was medicalised through the interaction with healthcare professionals, to which there was only a medically driven response. The anthropological methodology used for this study means that the findings are difficult to generalise further afield however the relatively large sample set and the ability to gather diverse perspectives from participants allowed Kaufman (1994) to gain new insights in to the effects of the healthcare interactions that occurred. This early study highlighted how identities were not only constructed for older people living with frailty through interactions with others, but that those identities could also be ‘successfully’ enacted within medical models.

The biomedical discourse was also apparent in Taylor’s (1992) study exploring conversation as the relational area in which identity is produced. Through observation and interviews with older people and younger people who lived with them, he found that frailty was constructed through conversation. Specific medical events served as markers to the decline of the older people, and their functionality was narrated and analysed in context of these events. Taylor (1992) concluded that the identity of frailty was used as an account for the behaviour of older people, its depiction created power differentials within relationships and enabled people to measure life progression. The older people in the study also used the ‘frail identity’ as a way to negotiate certain aspects of their lives such as eliciting praise and sympathy or physical care, in this way the construction of a frail identity may be beneficial for some, although they must negotiate this benefit against potential disempowerment. The concept of negotiation identified in this study feels reminiscent of aspects of the disengagement theory previously discussed in Section 2.1.1. Participants utilised the perceptions of frailty to alleviate themselves from some social roles. Disengagement from these roles, for them however became desired and the presentation of frailty was used as a reason for this disengagement.

The significant impact of frailty on healthcare systems and economy is clear from the general literature, and the cost to the individual physically and psychologically is also acknowledged, the response to this, however, seems to continue to be discussing ways to medically treat frailty. The development of the CGA in older person’s medicine alongside the evolution of the clinical concept of frailty appears to have somewhat cemented frailty’s roots in the medical idiom. The wider frailty literature is dominated by ways in which to define, measure and evaluate frailty in quantitative and medicalised ways. Nicholson et al. (2017a) in their commentary paper on the subject highlight the epiphenomenal undertakings such as frailty polices, checklists and frailty units that has been generated through this union. It would seem fair to assume therefore that the basis of understanding frailty starts in the medical sphere, however for many, sense of self-identity would not fit within this medical framework. A disparate arm of frailty is present, that of personal identity, one which cannot be easily shoe boxed into checklists or medical measures. This may account for the apparent paucity of frailty studies which specifically focus on identity within the medical literature. There is evidence however that the links between psychological and physiological wellbeing in frailty are significant. Gale et al. (2014) analysed data from 2557 older people aged between 60 and 90 and found that individuals with higher levels of psychological wellbeing (which could be interpreted as sense of self happiness) were less likely to become frail over the 4-year follow-up period and that there was a significant association between psychological wellbeing and risk of pre-frailty: 0.69 (0.63, 0.77). Examination of scores for hedonic (pleasure) and eudemonic (control, autonomy and self-realization) wellbeing showed that higher scores on both were also associated with a decreased risk of frailty. Participants had rigorous measures taken to define frailty via both physical measurements and validated questionnaires, although the large sample size added credibility to the results only 14% of participants were classed as frail. Additionally, it was unclear if psychological wellbeing was assessed prior to the development of frailty.

Previously Andrew, Fisk et al. (2012) had reported, in their secondary analysis of the Canadian study of health and ageing, that for each additional frailty-defining deficit, the psychological well-being score worsened by 0.3 points (0.29, 95% CI: 0.22-0.36, $p < 0.001$), independent of age, sex, education, cognition, and mental health. This sample set was much higher (n=5703) and both frailty and psychological wellbeing were defined by validated tools however the process of secondary analysis creates the potential for incomplete data. They concluded that frailty was associated with low levels of well-being, and that psychological wellbeing may be impaired by a frail identity. This may subsequently play a role in an individual’s subjective health and as Gale et al. (2014) infer may lead to increasing levels of frailty.

2.4.2.1 Consequences of medicalisation- the complexity of being frail

Considering frailty as a social construct rather than a purely medical paradigm may enable the complexities of frailty to be understood and identified. Kaufman (1994) initially looked to explore the tension between two apparently opposing healthcare paradigms that of medicalisation and autonomy. She highlights how advancements in medicine and technologies has created a culture of 'treatment', where social behaviours and personal problems can be viewed as medical problems to be 'fixed'. Older people are particularly vulnerable to this medicalisation due to the theoretical concepts of ageing and societal vulnerability highlighted in Section 2.1.2. Kaufman found that frailty was socially constructed within the healthcare interaction. Subjective experiences of the older person were interpreted in a medical service idiom, for example one woman, Mrs A, was diagnosed in addition to her medical diseases with a dirty house and too many pets. She had been brought to the team by her friend and neighbour who was concerned with several issues in Mrs A's life. Mrs A had previously rejected various interventions offered as she did not want anyone to have authority over her life. The neighbour described Mrs A as

> *Feisty, resilient, and resented any interference with her life or her affairs.*
>
> *(Kaufman 1994, pg. 51)*

Mrs A was visited at home by members of the health care team and subsequently discussed at a case conference without her present. It was decided, by the team, that she needed daily intervention, they agreed she would be safe to stay in her home if she accepted a professional clean, reduced the number of pets, accepted daily carers and physiotherapy and day centre visits. Mrs A was then later informed of the criteria decided, although she was friendly, she left not agreeing to the offer, the healthcare team started to put these systems in place anyway as they felt she would be safer. This transformation from lived experiences to lists of problems to be diagnosed and treated, and the negotiation of compliance regarding the rules about what ought to happen is the form of socially constructed frailty that Kaufman observed. This study is over 25 years old and services have changed however, the values placed upon the autonomy of the patient are still apparent.

Twelve years later Grenier (2006) explored older women’s lived experiences and narratives regarding frailty and similarly found that the identities of older people were often ‘totalised’, for example someone could be described as having a ‘frail appearance’ which impacted the perception of capability of numerous aspects in a person’s life. Although Grenier’s interview-based study was smaller (n=12), and was based in a specific region in Canada, similarities can still be drawn. Throughout the interviews Grenier found that although most frailty support is geared towards supporting physical care needs, the women talked more about their fears regarding loss of autonomy and independence. An example she gives is of Alice. Following Alice’s discharge home from hospital after a hip fracture, healthcare interventions focused heavily on safety, providing adaptive equipment and personal care. Although Alice recognised she needed this support, she expressed more concern regarding her experiences of her changing world, and her body/self-tension, where her bodily functioning threatens her perception and experiences of herself and her life world. A key finding of Grenier’s study was the concept of episodic feelings of frailty, the women participants felt that their identities were totalised and restricted by others based on these ‘moments’.

In both studies’ health and social care interventions, provided under the premise of safety and promotion of independence, overshadowed not only issues around self that were expressed but also created a sense of greater dependency and loss of personal autonomy for the older person. Grenier also surmised that the older women’s own understandings of frailty were physically focused and judged predominantly through physical limitations of the body, even though this was sometimes different to their lived experiences. The term frailty came to represent risk; and structured the services and interventions that the women were offered. These findings should however be viewed through the limitations of gender and that the age range of the participants was unclear, other methodological practices were also unclear such as the time frame and number of interviews conducted.

Over 20 years since Kaufman’s study, Skilbeck et al. (2018) noted similar experiences in their ethnographic study exploring meaning in the daily lives of older people with frailty. Skilbeck et al. (2018) observed interactions and undertook interviews with 10 older people and their community matrons in a City in the North of England. Participants were recruited through the community matron teams which Skilbeck et al. (2018) recognised may have influenced the interactions, particularly as the main researcher was initially introduced as a colleague rather than a researcher. Their findings highlighted the complexities of the lived experiences of frailty and the position older people find themselves in of constant adaptation. As in Grenier's study, Skilbeck et al. (2018) observed frailty being temporarily experienced by older people. This temporality is an area alluded to throughout much of the literature in this area. It is represented as having moments of '*feeling'* frail rather than '*being'* frail (Grenier 2006). By describing frailty as a feeling older people are constructing their frail experiences as fleeting and therefore perhaps trying to reinforce their identity, I will discuss this further in the next section, however in relation to the medicalisation of frailty this has impact. When frailty is reduced to medical/physical interventions such as providing walking aids, the complexities of frailty may not be acknowledged, for example, in Skilbeck et al. (2018) study participants linked the provision of equipment with getting old, a feeling which was not always experienced or perhaps only experienced temporally.

> *I didn't want a stick, because old people have sticks, I don't feel any different in myself, I don't feel old* *(Skilbeck et al. 2018 pg. 8)*

There is a sense of malleability of frailty that its medicalisation does not appear to respond adequately to. In Kaufman (1994) and Skilbeck et al's. (2018) studies, interventions are not initiated with the proviso that they could be temporary, there is no mention that the walking stick only needs to be used on the days a person is feeling frailer or that the provision of carers may be temporary post hospital discharge. When plans are developed there is a sense of inevitability that medical interventions construct. Reducing frailty experiences to medicalised formats only really affords a medical response, once that is initiated there may be limited scope for the older person to experience their temporary feelings of frailty without being deemed to be clinically frail and labelled as such. The risk here is that older people may not express their lived experiences, for fear of this medicalisation and lack of recognition of frailty as a felt experience not just an actionable problem to solve. This leaves scope for exploration in this area to further understand how medicalised responses to frailty may impact on the self and the engagement in such responses, and whether there is space for health professionals to respond in any other way.

The literature suggests a misalignment of the perceptions of frailty between health professionals and older people, when an older person's identity is reduced to a medical dimension there is risk of 'othering' that person. The findings from these studies are resonant with the theoretical perspectives on ageing discussed in Section 2.1.1, where frailty is linked with dependency and fear for the future. It is understandable therefore that the study data collected also suggest negative associations and resistance to the term frailty which I will discuss now.

2.4.3 Negative associations with frailty and resisting its notion

For many older people in these studies' frailty is something they recognise in others rather than themselves and was often perceived to be related to end of life and irreversible decline. Age UK and the British Geriatrics Society (BGS) (2015) commissioned a qualitative research study to gain insights into the understanding of frailty amongst older people and healthcare professionals not specialising in geriatrics. Unlike the other studies reviewed, this study was conducted over two fieldwork locations in order to minimise the potential for regional bias. Although it was not clear from the paper how participants were recruited, they report even gender splits, spread of socioeconomic levels and inclusion of black and ethnic minority (BAME) older people. While all the older people who participated lived in the community some lived alone and others with a partner. For the health professionals that participated the authors highlight their cross-section of experience and specialism which would potentially give broader perspective on the topic. Although the demographic scope of participants was broad, the numbers recruited were relatively small. *n*=3 older people without frailty were recruited in both sites with one triad interview conducted. In the South (*n*=5) face to face interviews were conducted with older people with frailty in comparison to (*n*=7) in the North. An additional focus group of (*n*=5) informal carers was also conducted in the South. *n*=8 healthcare professionals were recruited at both sites with a mixture of paired depth interviews and telephone interviews.

The researchers used face to face and telephone interviews at both sites for older people with and without frailty, their informal carers, hospital managers and non-geriatricians. The findings highlighted that the concept of frailty is understood very differently by the public and non-geriatricians compared to those who specialise in older person's medicine. For most, frailty was considered to be irreversible and therefore untreatable however, when the individual elements such as reduced muscle strength and fatigue were discussed participants could recognise potential for rehabilitation and improvement in these individual areas. Ultimately the older people in this study did not identify with the term frailty or see themselves as frail, instead their experiences of living with frailty were measured through their perception of day to day challenges they may face. This research would suggest that by using terminology such as *frail* and *frailty* healthcare professionals are less likely to engage older people in rehabilitative treatment plans. Non specialist health care professionals who took part in the study identified frailty as something which they know when they see, interestingly their interpretation of frailty was more in line with the older person's narratives in Grenier's (2006) and Skilbeck et al's (2018), where frailty is related to those approaching end of life and highly dependent on care, than the clinical operational definitions.

Nicholson et al. (2012) used psychosocial narrative approaches and psycho-dynamically informed observations to explore the experience of 15 older people in the UK, aged between 86 and 102 with frailty, living at home over a 17-month period. Participants were recruited through an older person's community care team and interviewed up to four times over the data collection period. As with previous studies, the participants did not relate to the terminology of frailty, rather they experienced frailty as a state of imbalance, a place where they experienced multiple losses and disconnections from their world. Loss of autonomy was linked to challenges to self-identity, the established routines of older people were jeopardised through their functionality, and for some, reliance on external support. This created feelings of hopelessness and invisibility, which appeared to impact on their confidence and their individuality. The literature suggests that older people with and without frailty have constructed concepts of frailty, elements of which they can experience but do not relate these to their total identity. Negative associations with frailty shape the way in which they view themselves and others. Undesirable experiences or concepts in relation to frailty generate dissociations from the concept and resisting its notion becomes an important belief for self-preservation.

Throughout the reviewed literature older people both with and without frailty expressed negative associations with its concept and distanced themselves from having frailty, even if they acknowledged symptoms of the condition. Older people demonstrated a strong aversion to the term frail, they do not use it to talk about themselves or their lives (Age UK and British Geriatric Society 2015). Interviews with older people with frailty conducted on behalf of Age UK found that conversations regarding frailty were difficult to navigate using the terms *frail* or *frailty* as most participants did not see themselves as frail (Ipsos MORI 2014). They found that older people were experiencing difficulties with activities of daily living however attributed this to a collection of symptoms associated with getting older such as fatigue and pain rather than collectively terming them as frailty. Perception of the rate at which deterioration happened to them differed between the individual and their relatives, relatives saw the onset of frailty symptoms gradually whereas the older people attributed deterioration to specific events such as a fall or infection (Ipsos MORI 2014).

These feelings of frailty around specific events are comparable to the way in which the older women in Grenier's (2006) study denied '*being frail'* but expressed moments where they '*felt frail'*, these moments were often linked closely to losses such as bereavement or fears after a health event such as a fall. Grenier (2006) found that these women negotiated their identities between being and feeling frail. Having moments when they felt frail was accepted, however by defining these as feelings rather than ways of being appeared to enable the older women to protect themselves from being defined as frail. Through this negotiation and resistance of frailty, the complexities of personal and emotional processes related to maintaining a sense of identity are highlighted and point towards a cultural aversion to frailty, particularly amongst women where stereotypical images of old age predominate societal concepts as discussed in Section 2.1.2.

Warmoth et al’s (2016) grounded theory study explored adults' perceptions of frailty and their beliefs concerning its progression and consequences. 29 participants aged 66–98 with varying degrees of frailty were interviewed in their homes or institutional settings. They similarly found that the conceptualisation of frailty varied amongst older people and differed from that used in a clinical context. Participants accepted that someone could be physically and psychologically frail, and depicted frail individuals as

“Hunched over, grey-haired, wobbly and slow (physically and mentally)”

(Warmoth et al. 2016, pg.1490)

Unlike other studies three of the participants did identify as frail, however they believed that this was due to factors outside of their control and predominantly linked to their age. Again, there was a sense of inevitability surrounding frailty, which once acquired, was irreversible. This view was supported by other participants who did not identify as frail, one woman who had other long-term conditions and cancer, and needed daily care, explained why she didn’t consider herself to be frail

“because I fight against it um I mean if I let myself go and didn't arrange things and didn't do anything I could become more frail, but I have the stimulus of people around”.
(Warmoth et al. 2016, pg. 1492)

It is important to note that participants for this study were recruited through a variety of community organisations where people were already engaging in social situations therefore the demographic was potentially narrow, and participants may have had more positive outlooks on life to those not engaged in such groups. Additionally, nearly all the participants, although retired, would be classed as professionals, which may have influenced the responses. Nevertheless, these narratives suggest that older people may see frailty as somewhat of a dichotomy, on one hand it is seen as an inevitable consequence of age, yet resisting its notion suggests that there is also a belief system that it is somehow avoidable. There is a sense of internal battle, by resisting frailty they can ‘fight against’ this inevitable force, because once frailty has arrived it is terminal and they must surrender to it, as there is no other option. The onset of frailty is attributed then to a lack of fight or will power to overcome on the part of the older person and generates the construct of personal blame. This is mirrored in the theory of successful ageing described previously in Section 2.1.1, where individual responsibility to achieve potentially unreachable criterion generates feeling of personal failure and reduced sense of self-identity.

Having discussed societal perceptions of ageing and their associated discourse, it is not surprising that many older people display aversion to being diagnosed or labelled with frailty. Notions of terminality and inevitability surrounding frailty also supports the impression that many people associate the term with end of life and something to fear. Throughout the literature frailty was often perceived as something that other people had, other people that were considered to have worse health than themselves were deemed frail by participants and the concept was often linked to death.

"To me a frail person is more like a skeleton that can't move."

(Ipsos MORI 2014, pg.17)

Similarly, Grenier (2006) also found that participants closely connected frailty to mortality and when asked about frailty many of them talked about their parents at the end of life.

"I don't think it's anything to do with age, but I would say most of frail people are older people, your body is worn out, you are frail. My mother died; she was 101. She was frail when she died. (Martha)."

(Grenier 2006, pg. 307)

Hörder et al. (2013) interviewed 24 older people (77-90 years old) in Sweden regarding their thoughts and experiences on successful ageing. There were more male participants (n=15) than in the other studies reviewed, however 18 of the participants had been recruited from a prior healthy ageing RCT, and therefore perhaps held a more positive view of ageing than some other samples. Using content analysis, they found that denial of difficulties was a mechanism used by many. Several of the participants laughed when discussing death or illness and the researchers interpreted this as a way of participants distancing themselves from these ideas. They concluded that successful ageing was in part seen as an ability to keep fear of frailty at a distance. By attempting to keep frailty at arms length older people are actively establishing a non-frail identity, if they are then labelled with frailty by others, including their healthcare teams, feelings of inequity, injustice and resentment can arise. Through hiding and negotiating symptoms older people appear to be attempting to maintain their self-integrity. Many older people felt these labels were unfair as they perceived their conditions that had elements associated with frailty as transitional (Grenier 2006; Warmoth et al. 2016). Being labelled with frailty was offensive for many older people, as they perceived this to mean a permanent status and meant that they became the ‘others’, the ones with no hope (Grenier 2006; Age UK and British Geriatric Society 2015; Warmoth et al. 2016).

Associating frailty with death could mean that older people are positioning themselves on a life trajectory, by using frailty as an endpoint they may be creating a sense of self-identity and where they consider themselves to be situated on the journey of their lives. By accepting frailty, they may feel that they are accepting the end of themselves. This thought process also falls in line with the previously discussed cultural perceptions of the third and fourth age trajectories discussed in section 2.1.1. What the concept of death means to people, although outside the scope of this review, may significantly contribute to this avoidance. If developing frailty is attributed to failure of an individual to maintain their autonomy and independence, then accepting it could lead to feelings of existential failure and loss of sense of self (Lawton 2000). Frailty becomes a label of failure, with the totality of their worth being death.

Defining frailty through focusing on the body’s capabilities means that older people’s identities are at risk of being reduced to their functionality, their frail body becomes their total identity. I previously discussed Kaufman’s (1994) study where the interactions with the healthcare team constructed the frail identity of older people, however it is also evident that totalisation of the frail individual does not only happen from healthcare professionals but also from other older people themselves. The argument for this lies in some of the narrative interviews in Warmoth et al’s (2016) study where there was clear objection from some participants towards people who defined themselves as frail, they were described as ‘wallowing’ in it or exaggerating their frailty so people helped them. Identifying as being frail was considered self-indulgent and for personal gain. Lund and Engelsrud (2008) in their ethnographic study of social Day Centres in Norway also found that many of the older people who attended, experienced a tension between their attitudes and their actions. 100 hours of participant observation data over a three-month period were collected, which focused specifically on the activities and interactions of older people at the Day centre. They found that although older people were appreciative of the opportunity to meet others and experience feelings of community, several strategies were also put in place by the older people to distance themselves from the beliefs they held about other older people that attended the centre. They reinforced negative stereotypes of the Day centre as a place where people go when old or before a nursing home, one man in his 80s did not return as he did not want to be with other old people. Other observations included criticisms by some older people of others within the centre, Lund and Engelsrud (2008) interpreted this as ‘othering’ and distancing within the group. By criticising physical or psychological ‘signs’ of ageing in others i.e. how a person walks or looks, they are attempting to maintain a positive image of themselves and distance themselves from those signs of ageing. The ageing body in this case becomes the symbol of a person’s identity, ‘failing’ bodies appear to be used as a reflection of an individual’s ability to maintain youthfulness, perpetuating the previous theoretical ideologies that your physical functionality is a measure of your successful ageing.

The problem with these types of ‘othering’ or totalising behaviours and perceptions is that they can contribute to the development of a frail identity for older people. In Warmoth et al’s (2016) study they found that being labelled as ‘*old and frail*’ by others contributed to the development of a frail identity, this was evident in a social context i.e. loss of interest in participation in social events and increased stigmatisation. And in a physical sense where people developed poorer physical health. The process of othering can result in predominant negative stereotypes where older people have less to contribute to society, are less competent and more dependent (Van Dyk 2016). Collectively these types of thought processes can create societal attitudes towards older people that Abrams et al (2015) describe as *benign indifference*. Their research suggests that ageism is indirectly manifested within society and embodied in behaviours such as disrespect and exclusion rather than directly displayed as through abuse. As in Grenier’s (2006) study participants linked seeing oneself as frail with becoming frail and that acceptance of the label of frailty would result in physical and psychological decline.

2.4.4 Maintaining identity as a self-management process frailty

It is clear from the limited literature in the area of frailty and identity that older people and others strongly associate frailty with negative connotations, weakness in body and mind and terminal dependency. We have seen that many older people ‘fight’ the notion of frailty in order to separate themselves from these negative connotations (Grenier 2006; Lund and Engelsrud 2008; Warmoth et al. 2016). In order to maintain a sense of self-identity the literature suggests that older people do not simply resist the notion of frailty through denial, rather they employ strategies to overcome challenges that they deem important in order to maintain their identities (Grenier 2006; Nicholson et al. 2012; Warmoth et al. 2016; Skilbeck et al. 2018). Warmoth et al. (2016) found that several strategies were employed by older people to resist frailty, firstly people attempted to remain active, physically, mentally and/or socially. Even if this activity was at lower levels than previous, older people with and without frailty considered this important. Older people tended to focus on their abilities rather than infirmities. ‘Doing things’ was a belief held that would delay the onset of frailty, linking to the previously discussed theories of activity. Another strategy that older people employed was relating loss of functionality to a particular part of their body or illness, for example falls could be caused by weak legs or imbalance due to a stroke. By distinguishing between specific health conditions and frailty older people considered themselves to be resisting it.

Additionally, older people compared themselves to others that they considered worse off than themselves, through doing this they were able to focus on their capabilities and promote themselves in a more positive light to others. Nicholson et al. (2012) further highlighted the contribution of perception of others on the complexity of older people being able to maintain their identities. They found that people with frailty are often faced with concern from relatives as to their capabilities and therefore need to navigate not only their own feelings about their condition but also those of their families.

Strategies such as ‘pacing oneself’ (Nicholson et al. 2012) and maintaining routines (Nicholson et al. 2012; Skilbeck et al. 2018), are noted amongst the literature and appear to contribute to the maintenance of daily routine and sense of self-identity. Anything that may disrupt these strategies may be felt as a threat by the older person to their fight and consequently to their personhood. Nicholson et al. (2012) noted the difficulties of sustaining these important routines if outside agencies became involved. Older people often felt having carers was disruptive to their norms, and in some cases found it easier to decline help in order to maintain their autonomy over their routines, even if these routines became harder to carry out. Families and healthcare professionals found refusal of input difficult to accept at times, this concept of disruption sits well with our previous discussion regarding theoretical perspectives of ageing. Independence appears to be valued by all, yet if older people with frailty attempt to remain independent when others perceive them to need support then they are often considered to be disengaged. Coleman et al (2001) also found strong examples of individuals expressing intervention as threat to their identities. They carried out case study analysis on 5 individuals chosen from a large, 20-year longitudinal study in the UK. The aim of the study was to explore theories of aging over a life course in older age. Overall, the researchers found that older people maintained their identities through processes of adaptation and assimilation, and although all the individuals in the cases studies displayed evidence of this type of adaptation as their lives progressed, some expressed clear rejection to loss of independence. Mr Peck for example, strongly resisted the concept of moving into a care home after his wife died and he experienced a period of depression stating

> *“I don’t want to go into a home. Don’t break my heart. This is my home, and this is where I want to stay”.* *(Coleman et al. 2001, pg. 837)*

Five years later his mental health seemed to have improved and he was able to relate his fear of going into a home with lack of independence, something which he values so strongly that he would rather die than lose it.

> *"I'm a very independent man. I will not lose it at any price. I'm scared to death about my independence being taken away from me. . . I'd like to go to sleep now and not wake up tomorrow. You've got to accept what you can, but I've got a fear of collapsing in the street. It's stinking pride!"* *(Coleman et al. 2001, pg. 837)*

Mr Peck identified as a proud man, an identity which appeared to outweigh the risks that were highlighted by himself or others. Three years later at the age of 90 he continued to live at home but was immobile outside of the house and supported by carers, he accepted this new routine however, and still maintained a strong sense of autonomy over his health as after a number of operations on his prostate he declined the option of removing his testes as he *"still wanted to look like a man."* , stressing that he still enjoyed female company. Skilbeck et al's (2018) study likewise identified how older people structure and maintain their lives through daily routines. They found that individuals experienced frailty in terms of fluctuations in ill-health and disruptions to their daily living, frailty therefore was felt as a dynamic process, where one could transition in and out of it. Participants described periods of feeling frail, which support Grenier's (2006) distinctions between feeling and being frail. Feelings of frailty centred on fear of the future and uncertainty of their bodies for example; becoming fearful of walking after a fall, yet these feelings were mostly temporary, and appeared to be overcome as the older person re-established routine and confidence. The ways in which older people make sense of their ageing process may influence their attitude towards outside intervention, especially if that intervention threatens to disrupt their established coping mechanisms. This will have significant implications for practice which I will discuss now.

2.5 Implications of understanding for policy and practice.

If routine is as important to the maintenance of sense of self-identity in frailty, as it appears to be, it is particularly relevant when considering healthcare settings where the pace and routine is generally structured by the setting rather than the older person. In health and social care, theoretical frameworks such as person centred care have been proposed to support a positive sense of identity and recognition of the individual (Dewing and Garner 1998; Luckhurst and Ray 1999; Ford and McCormack 2000). Person centred care aimed to move away from a purely medicalised reductionist view, particularly of older vulnerable people and those with cognitive deficits, yet how it is applied in healthcare settings is still largely dependent on the adopted assessments and tools used by a service and the thought processes of the clinician. For example, many of the common quality of life assessments used with frail older people (SF 36 and EuroQol) were constructed based on medical outcome measures and give little scope for individuality (Carr and Higginson 2001).

Health and social care services for older people have seen significant interest, investment and policy change over the last two decades, with aims to meet the increasing demographic demand for support services. In 2001 The National Service Framework for older people (NSFOP) (Department of Health 2001) intended to standardise care, focusing specifically on organisational barriers to access care, ageist attitudes towards care provision and inequality in service provision (Department of Health 2001). Nevertheless, as discussed in Chapter 1 it failed to show significant societal impact on the understanding and provision of health care (Manthorpe et al. 2007). After the NSFOP a number of UK government policies relevant to older people were established with focus on independence, wellbeing and choice (Department of Health 2005a), supporting long term conditions (Department of Health 2005b) and individuals taking control of their own care (Department of Health 2006). Despite these policy developments. implementation in to practice appears to have been slow (Cornwell 2012; LLoyd 2012). Fifteen years after the NSFOP was proposed, reports suggest that effective interventions for most people with frailty remain elusive (British Geriatric Society and The Royal College of General Practitioners 2015). Indignities and lack of basic care provision brought to light through the Francis report in 2013 further exposed the policy verses practice gaps (Francis 2013).

In 2014 the UK practice guidelines for frailty were published recommending a frailty assessment should be carried out at all the encounters between health and social care staff and older people in community and outpatient settings (Turner and Clegg 2014). The two part strategy Fit for frailty 1 and 2 (Turner and Clegg 2014; British Geriatric Society and The Royal College of General Practitioners 2015) differentiated between older people and those with frailty, rejecting the assumption that frailty is an inevitable part of ageing. Additionally, it recognised the fluctuating nature of frailty and compared it to other long term conditions that are not static in nature. They talk about the need for a holistic medical and multidisciplinary review based on the CGA and although many of the assessments remain focused on the physicality of frailty, they do suggest discussion with individuals regarding the impact of the illness.

Since 2017 GPs are required to identify patients over 65 years who may be living with frailty. In their opening gambit on coding frailty NHS England (2017) describe it as

"(frailty is) the most problematic expression of ageing we are facing in modern healthcare". *(NHS England 2017)*

Through proactive identification of frailty, the aim would be for those deemed to have severe frailty to have an annual medication review and all with frailty to have an annual falls review. They do acknowledge that although electronic coding can identify those at risk of frailty, the diagnosis itself needs to be based on the judgment of the clinician. It would seem vitally important therefore for clinicians to recognise the significance of sense of self-identity in frailty and not purely focus on frailty as a problematic biomedical issue. This literature reviewed suggests that this type of mass identification of frailty may be, at best, rejected by the individual, and at worst, create a schema that negatively effects both their physical and psychological health.

Considering the perceptions and beliefs systems identified in this review it is unclear how people living with frailty can be effectively supported if they do not consider themselves to be frail. Clarity about how healthcare interactions can support the identities of these people within these frameworks is missing, yet vitally important if healthcare policies and strategies are to be achieved. The literature suggests that the current culture surrounding frailty, both within and outside of healthcare settings, continues to be dominated by medical functionality and negative associations. Although the overture of UK policies around frailty appear to promote independence and remaining in the home environment, they are underscored by a focus on risk and 'surveillance' by the healthcare teams. Feeling that they are being constantly surveyed however arose as a reason that older people did not want to engage with intervention (Kaufman 1994; Grenier 2006). Ultimately if health professionals perceive risk in differing ways to older people then the autonomy that these policies is aiming to create is unlikely to be achieved through continued surveillance and intervention.

The reviewed research suggests that supporting a sense of positive self-identity in frailty has become the prerogative of the older person, the medicalisation of frailty and focus on the failing body has been the emphasis of health promotion objectives where increasing activity is promoted as a personal choice (Department of Health 2005a). This leaves scope to understand how the interactions and cultural constructs of frailty within healthcare settings may foster a more positive sense of identity for older people with frailty, whilst acknowledging the complexities and individuality of a persons lived experience, in order for individuals to experience and engage in effective care that meets their needs and capabilities.

2.6 Summary and research implications

This chapter details how identities of older people with frailty are structured within larger theoretical perceptions of ageing. The first section of this chapter highlights how several influential theoretical perspectives have shaped current societal views, understandings and perceptions of older people with frailty and healthcare practices aimed at optimising their health. Perceptions surrounding the successfulness of ageing are framed by an individual’s status of independence, lack of need of support and power of autonomy. Fear of dependency can add burdensome feelings to individuals who often already feel they are a drain on society. Older people must navigate a paradoxical world in which they face the medical complexities and negative perceptions of frailty and ageing, against consumerism promoting youth and definitions of positive ageing. They are living in a world where capability and independence is praised and valued with age. The ‘others’, those who are not perceived to be achieving these criteria, can feel excluded from being given the opportunity to be seen as capable, as biomedical frailty criteria continues to dominate healthcare services.

Continued focus on physical manifestations of frailty and related measurements and treatment options perpetuates totalisation of the older person, where focus lies on problems to solve and frailty becomes the total identity. The literature highlights that frailty can be socially constructed through interactions with others, this perspective suggests a more complex social dimension to frailty which cannot be reduced to a set of bodily functions or attributes. Frailty services based on medicalised assessments of predominantly physical attributes are at risk of pigeonholing an older person, and as that person progresses through their frailty journey, it may be more difficult for health professionals to see past their frail label.

It is clear from the limited literature in this area that older people do not relate to or construct frailty in the same way that it is clinical defined. Older people show antipathy towards the label of frailty and related terminology, it is often associated with end of life and high dependency by them, their families and society generally. Older people acknowledge its existence but use it as a descriptive term for others that they see as physically worse than them. Frailty is something that happens, but to others. There is a sense of resentment by those who have received a frailty diagnosis that this is unfair as, although they may have feelings of frailty, this is generally seen as a transient state. By labelling someone as clinically frail social constructs are developed and instilled which can lead to stereotyping older people and risking negative internal perceptions for the older person which may impact their treatment or rehabilitation. Paradoxically identifying patients with frailty in order to optimise their potential can lead to those same patients seeing themselves as failures. Older people with frailty attempt to maintain their sense of self-identity whilst navigating the complexities highlighted, through implementation of strategies which aim to provide routine and consistency in their lives. These strategies are vulnerable however to outside influence such as healthcare interactions which often hold little flexibility for an individual’s current routine.

In recent years the UKs health and social care infrastructures appear to have made moves towards a focus on the identification of people living with frailty and created systems which aim to promote personalisation and autonomy in their life choices and clinical assessments. However, both the discourse and the structure of these assessments continue to objectify frailty and medicalise its meaning even in the context of psychological and social well-being, with subjective experiences and perceptions of frailty being interpreted in a medical/social service framework.

Perceptions surrounding ageing health and frailty are not static but dynamic social constructions, they are subjective and draw on a wide range of factors to formulate context. This review suggests that throughout the complexities of their worlds, older people with frailty work hard to overcome feeling frail or being labelled as frail. Through focus on their current abilities older people appear to be able to navigate this fluctuating journey through self-imposed strategies involving routines and rituals. However, the reality of frailty is that outside intervention is often needed in order to support deterioration of the physical body and these routines are often challenged and disrupted by their own body and by others intervention. How these routines and maintenance of self are managed within the home environment has been explored, yet it is unclear how, and if, these strategies are the same when faced with similar challenges in a healthcare setting. Understanding the personal experiences of frailty of both the older person living it and those interacting with them in this environment, and the way in which frailty is culturally constructed through healthcare interactions would potentially enable us to support individuals to maintain their identities and personhood in the context of their daily lives and routines. Ultimately this may hold greater space for the acceptance and engagement in rehabilitative treatments and better outcomes for the older person.

Amid all of this, older people with frailty continue to be assessed, diagnosed and treated in healthcare practice. What remains unclear is whether the discursive and behavioural processes within a frailty-based healthcare setting positively or negatively contribute to the sense of self-identity of older people with frailty and reflect the perceptions of wider society. Additionally, understanding how the processes linked with the construction of sense of self-identity may relate to and impact upon engagement in healthcare services would seem beneficial. There is also a need to understand what a positive sense of self-identity looks like for an older person with frailty and if a positive sense of self-identity is needed in order to fully engage in current services.

Ignoring these wider social perceptions, interactions and conversations risks greater disconnection with the very people who would most benefit from targeted frailty services. The lack of clarity regarding these issues means that there is scope to explore how frailty is understood within a healthcare environment that is currently providing such services and how the cultural construction of a frail identity may impact on this.

2.7 Situating my research: Research aims and objectives

This review drew upon a diverse range of literature, exploring broad areas of perspectives of ageing and social discourse. There is a growing body of literature relating to frailty in the UK, however this appears limited in the area of sense of self-identity, particularly within health research. The current research shows that the lived experience of frailty in the home environment is complex and involves much stronger psychological and social elements than initially believed (Grenier 2006; Nicholson et al. 2012; Skilbeck et al. 2018). There is space within the literature to explore how these experiences are played out within healthcare settings, particularly since frailty specific policies have been implemented in the UK. My research will continue to focus on community dwelling older people with frailty, adding to this body of research, yet I will explore the cultural interactions between older people and their healthcare teams within an outpatient Day Hospital environment, a service where frailty assessments are conducted and interventions decided upon and received. By understanding ways in which sense of self-identity is constructed and maintained in this area, I hope to determine key processes which could be used to support future best clinical practice in frailty services.

2.7.1 Research aim

The aim of this study will be to understand how sense of self-identity in older people with frailty is understood, constructed and enacted within an NHS Day Hospital setting. This will be achieved through exploration of their socio-cultural experiences of care, the understandings and beliefs of the healthcare team and the cultural environment they operate within.

2.7.2 **Research Objectives**

- Understand the discursive and behavioural processes which contribute to the sense of self-identity of older people with frailty within the Day Hospital.
- Understand how the processes linked with construction of sense of self-identity in relation to frailty relate to engagement in services.
- Determine what processes need to be in place to support a positive sense of self-identity for frail older people.
- Recommend effective strategies for positively supporting sense of self-identity in a healthcare setting.

Chapter 3 Methodology

"Ethnographic research, whatever else it is, is a form of human relationship."

(MCCarthy Brown 2001, pg 12)

3.1 Chapter Introduction

The previous chapter presented a narrative review of the current literature surrounding frailty and identity, it highlighted that there have been relatively few studies that have explored the construction and deconstruction of the identity of older people with frailty within a 'real life' healthcare context. The majority that have explored identity in this population have approached it from a narrative viewpoint in order to illuminate the lived experience of those with frailty in their home environment or their lived experiences in other social provision such as Day Centres. The following four chapters outline the qualitative research methodology and ethnographic research process chosen for this study. In this chapter I discuss the development and self-recognition of my epistemological viewpoint as well as concepts around the theory of symbolic interactionism and how these were used as the foundation for my methodology. I highlight the relevance and application of ethnographic enquiry in relation to the aims and objectives of the study and my epistemological viewpoint. I give a brief history of the use of ethnography in a healthcare setting and explore the strengths and limitations of ethnographic methodology, discussing the concepts of insider/outsider relationships, my own positionality and association with the research.

3.2 Understanding how we know what we think we know.

When deciding on the most appropriate research methodology for this study I needed to consider not only the research questions but also my assumptions about what constitutes reality, evidence, data and knowledge. The philosophical concept of ontology centres around the nature of reality (Blaikie and Priest 2017), when we are seeking to answer research questions, we are really looking to find answers and gain knowledge about a 'reality' that exists external to ourselves (Glattfelder 2019). The ontological consideration for the researcher then is positioning themselves and their belief system with regards to the nature of reality. Several ontological outlooks are discussed in the literature (Poli and Seibt 2010; Effingham 2013), but underlying most are two approaches, positivism and interpretivism. When using a positivist ontology, it is assumed that reality is external, independent and objective. From this position there is a single reality irrespective of the researcher's perspectives or beliefs (Levers 2013). When using an interpretivists approach there is the assumption that there is no single objective reality, that multiple realities exist and are relative, dependent on socially constructed understandings and values attached and attributed to things (Mackenzie and Knipe 2006; Blaikie and Priest 2017). Epistemology is a philosophical branch relating to the nature of how we gain understanding of reality or knowledge, how it is justified and rationalised, and what makes that knowledge legitimate and valid (Johnson and Duberley 2000; Pope and Mays 2007; Saunders et al. 2009). There are several epistemological positions in social research, the most common being;

- **Objectivism** (which argues social reality is external to us and others. Meaning and truths are objective),
- **Constructivism** (where people construct their knowledge through their interactions and experiences. Meaning and 'truths' are constructed) and
- **Subjectivism** (where an external reality exists but is imposed on the object by an individual's consciousness. Meaning and 'truths' are subjective). (Ab Rashid et al. 2016; Lincoln and Guba 2016).

During our daily life we make several conscious and unconscious assumptions, based upon our own ontological and epistemological beliefs and values which affect the decisions we make (Blaikie and Priest 2017). As researchers these beliefs, values and assumptions will influence the research we undertake and the methodology and methods we choose (Saunders et al. 2009; Denzin and Lincoln 2011; Slevitch 2011). How we arrive at particular questions, how we choose to explore them and how we evaluate the subsequent research will vary according to our ontological and epistemic commitments (Johnson and Duberley 2000). It is therefore imperative to recognise and consider our own viewpoints, recognising axiological assumptions (a person's subjective values, intuitions and biases) which will influence the research and the strength and limitations of the subsequent findings (Saunders et al. 2009).

3.2.1 Continuum of knowing

Qualitative research is based on interpretivism and constructivism, both of which stem from an ontological view that reality is socially and psychologically constructed or interpreted, as such multiple realities exist and are continuously recreated by a person depending on their intersubjective understanding of an interaction or situation (Slevitch 2011). In this case the researcher and the researched are interdependent and actively connected, consequently research findings are mutually created within the context of that environment. From this perspective social reality cannot be free from a person's own values, beliefs and perceptions and can only ever be described as we perceive or interpret them. The pursuit of objective facts and generalisability is considered unobtainable, and rather the transferability of findings becomes a more significant endeavour (Blaikie and Priest 2017). The strength of transferability is based on the depth of the findings and the contextual detail all influenced by the methodology and methods chosen to conduct the study. To the novice researcher the concept of epistemology can appear daunting, at first, I thought epistemology was something I needed to find; to add to my knowledge base before I began any research. What I discovered was that epistemology is something we already have, the key is acknowledging and understanding it. In order to understand and develop this I started with a period of self-reflection. Later in this chapter I discuss my positionality within the research, the exploration of which held space for the type of personal reflection needed in order to understand our beliefs around knowledge.

The concept of 'knowing' can be described using a continuum with varying levels of knowledge, at one extreme there is ignorance (an absence of knowledge), and at the other certainty (which is fixed and firm knowledge) (Klagge 2018). Most people would recognise that there are numerous things we are ignorant about and very few we can attribute certainty to, yet we live between these two extremes making assertions that correspond to our epistemic values. I started by exploring my world views. I identify with strong values relating to interpersonal connections and am a believer in '*gut instinct'* or *‘felt sense’*, in fact I have often spoken about the importance of this to nursing students in practice. Felt sense or embodied knowing refers to the notion that a person can develop a bodily sense of meaning which they may not be able to express or articulate (Gendlin 1981), for example many nurses will have experienced looking at a patient and thinking they look a bit ‘off’, there may not be a particular thing that they can identify, but the bodily feeling they experience, concern, increased heart rate, will likely lead them to explore and investigate things a bit further. As nurses and health professionals much of our clinical experiences are pragmatic, i.e. we know by doing and seeing what works (Polkinghorne 2004), nevertheless I believe that our understanding of how something ‘works’ is somewhat subjective and based on our sense of reality and the values we place on things. For example, my encounters observing the way in which younger and older people interact with medical staff differs considerably. In my experience older people tend to be compliant and submissive toward medical staff suggesting they have attributed a value and meaning to their identity, role and stature, which is perhaps different from people who are younger. My epistemological stance then starting this study was that individuals will interact with others and construct their world based on values attributed to things, and that these values arise from their interactions and the values that have been placed on them and that they have adopted within the society they live.

3.2.2 Symbolic interactionism as a way of knowing

The concept that people act towards things on the basis of meanings they attribute to them is the first premise in the theory of symbolic interactionism (Rock 2001; Blumer 2018). Having found a sense of cogence between my epistemology and symbolic interactionism I drew upon this theoretical framework to guide my methodology. The basic premise of symbolic interactionism is that a person’s ideas and beliefs develop through social systems and will vary and can change dependent on their environment and interactions with others. In other words, behaviour and values are modified dependent on interactions with others and their social world (Blumer 2018). From this perspective it can be accepted that within and outside of the Day Hospital people are constructing their social world through interactions with each other, objects and their environment. Staff working within the unit may embody and be influenced by one social system, whilst an older person embodies another. Yet the interaction between the two will construct a way of understanding and attributed values, and the interpretation of these interactions will affect the behaviour and connections of both parties and constructed cultural practices that occur. How individuals and groups interact with one another create symbolic worlds, where people enact their perceived roles. Symbolic interactionism suggests that society is created through repeated interactions and how these interactions are interpreted and acted upon creates meaning for individuals, and society as a whole. As individuals we act upon a shared understanding of meanings within our social contexts.

I am by no means a sociologist, so I tried to play out a common scenario I have witnessed in practice to see if this approach made sense to me and would support my objectives and questions. An older woman (let’s call her Sue) comes to a falls clinic for therapy following a fall. She is anxious about attending as she has had a previous bad experience in a hospital. To her the hospital represents sickness, lack of independence and paternalism. As she waits for her appointment, she talks to others in the waiting area about her anxieties. Another patient, (let’s call him Jim) tells Sue that he was also anxious but has received helpful therapy which has improved his walking. Sue is still dubious but after a few weeks she notices her mobility has improved and as social interactions with staff and other patients have increased, so too has her confidence. Her anxiety has lessened and her perception and meaning attributed to the hospital has changed, along with her level of engagement.

Understanding the principles of this theory enabled me to better recognise and understand my ontological and epistemological perspectives; that we come to develop knowledge through social interactions with others and the world around us. Furthermore, we can embody multiple versions of self, dependent on who and where we interact with others and the values we attribute to these interactions. This viewpoint rejects the concept of an objective truth or single reality, as through this lens these are unobtainable, as beliefs are value laden and constructed through our societal engagements. From this premise older people in the Day Hospital will have constructed an identity, a version of themselves, based on their personal values, beliefs and perceptions of their world. These perceptions will not only be based on their prior understandings of their own social roles, in a given situation, but also of how they believe others are perceiving them and the roles and identities attributed to them by others.

Their social connections and the roles they adopt during interactions may be influenced by symbols associated with ageing and frailty. In this context the term symbol does not simply refer to a symbol (e.g. an object), but rather the meaning we attach to objects and experiences, in a world where objects and experiences have no inherent or intrinsic meaning (Tan et al. 2003; Blumer 2018). So, symbols can be physical objects such as mobility aids (my Mum point blank refused to use a walking stick as she thought people would think she was old), or life events such as episodes of ill health or bereavement, or even perceived attitudes towards something by individuals or wider society. We don’t have to look far to face media representation of older people as ‘burdens on society’ and in particular to the NHS (Inman 2019; Triggle and Butcher 2020). From a symbolic interactionist outlook if society attributes values to older people that they are of lesser worth or burdensome, we could presume that people in that society may act in a derogatory or paternalistic manner towards the older person, in turn the older person will modify their interaction with that wider society accordingly. The alternate is also the case, where a society attributes worth to older people, we could assume that the older person will modify their interactions to live this worth.

3.3 Ethnography as epistemology: finding a methodological fit

Having established my epistemological viewpoint and found a congruent theoretical framework I looked for methodologies which would support these philosophical underpinnings and answer the research questions posed. I first considered interpretive phenomenology. Interpretive phenomenology is a research methodology which focuses on the lived experience (Flood 2010). Phenomenology recognises individuals as embodied, social and cultural beings (Zahavi 2018), and as such looks to understand the phenomena under question from the viewpoint of the individuals. Although an understanding of the viewpoint of individuals would be valid and important in this study, I was really aiming to understand how these individuals lived experiences interconnected to create a cultural world and how this culture helped construct their identity. Returning to the underpinning epistemological principle that all interactions are modified within a given interaction, I felt the use of interpretive phenomenology may restrict my abilities to gain insight in to practices within the Day Hospital beyond those which participants chose to tell me or felt were important.

An alternate research methodology of ethnography aims to describe and interpret a social world and culture. Like interpretive phenomenology it looks to understand what people or ‘actors’ within a social world know and experience. But additionally, how this knowledge is used by those actors in order to participate within it (Fetterman 2019; Kirner and Mills 2019). Through observations and interviews ethnographers can illicit descriptions of rituals, relationships and discourse which can build a bigger picture of the culture within a community (Maggs-Rapport 2000). Green et al. (2012) refer to ethnography as a *logic in use*, it is a recursive and iterative process of abductive reasoning whereby the ethnographer seeks to find the most likely explanation for a set of behaviours based on observations. Ethnographers are in other words striving to find ‘*a way of knowing’* within a different world. Consequently, some authors propose ethnography as epistemology, a philosophy of research itself rather than a set of methods (Agar 2006; Green et al. 2012). I chose to adopt the principles of ethnography as a research methodology as I felt it suited my epistemic notions and afforded me the methodological flexibility needed to understand and identify how older people with frailty perceived, understood and enacted events of daily life within the Day Hospital.

3.4 Ethnography: more than a set of research methods

Ethnography as a research approach has a rich history within the social sciences. It is a complex design of qualitative research which generates an understanding of culture within a group and setting (Reeves et al. 2008) and has been described as the art and science of describing a studied group or culture (Fetterman 2019). The two key features of both definitions are culture and groups however there remains some ambiguity surrounding what ethnography is and isn’t, in part this is due to the use of the term both as an end product of a study and as the methods used within a study (Hammersley and Atkinson 2019).The foundation of ethnography is exploration. It is different to several other qualitative research designs as it generally adopts a very open and fluid approach, because of this an initial area of interest will be refined over the period of the research as understanding of the behaviour within a group becomes clearer (Hammersley and Atkinson 2019). The emphasis on culture is what differentiates ethnography from other approaches, the term culture really describes ‘the way of life of a group’ (Holloway and Galvin 2017), the behaviours which are socially constructed and enacted.

From a methodological perspective there are some strong principles and features which are usually present; firstly, Ethnographers start with the premise that social life is meaningful, and that people engage with one another through interpretation and understanding (Atkinson 2015). Secondly action and identities of actors within an environment can only be analysed within a cultural context or within the field, and these identities are not fixed but changeable. Thirdly actors are socially competent and knowledgeable about their own culture, using tacit knowledge in daily life (Atkinson and Pugsley 2005). Perhaps the most pertinent feature of ethnography is that the research occurs in ‘the field’, i.e. the behaviour of individuals and groups are studied in context of their lives rather than in situations structured by the researcher or relying on participant accounts alone. Being in the field allows immersion into an environment to gain a deep knowledge about the intricacies and inner workings of a group of people and offers the opportunity to observe behaviour or beliefs through actions which may differ from those shared verbally (Fetterman 2019; Kirner and Mills 2019).

Qualitative research methods are usually inductive and focus on meaning (Savin-Baden and Major 2012), ethnography provides engagement in the life world of others that offers context to the shared cultural nuances and complex relationships within that world. In the following chapters I detail the practicalities of the ethnographic methods used in this study along with their rational, but I felt it would be of value to briefly discuss methods here as they are so closely entwined with methodological principles in ethnography.

Participant observation is almost universally accepted as a central feature of ethnography (LeCompte and Schensul 2010; DeWalt and DeWalt 2011). It is a method of data collection which allows the researcher to observe and take part in the activities of the individuals and groups being studied in their natural setting. DeWalt and DeWalt (2011) note that although most fieldwork involves observing, the difference with participant observation as a method is that information is gained from the participation and interaction with the group or activity. The ability to spend long periods of time immersing myself within the setting of the Day Hospital enabled the observation of behaviours, discourse or rituals which were sporadic or emerged as sequential patterns of behaviour that may not have been observed or identified using other methods. However, as Gobo (2008) highlights novice ethnographers face a problem that there is a lack of explicit explanation about what and how to observe and what to record, this is understandable as ethnography has a lot less control over the direction that the research may take than other methodologies. The researcher is effectively acting and reacting to unpredictable events and so detailed strategy is impractical and 'how tos' need to be somewhat speculative (DeWalt and DeWalt 2011). The observation of these sometimes subtle, adopted behaviours, interactions and relationships has enabled me to gain a meaningful understanding about the social world of the Day Hospital through the experience of playing a shared role in their world that is normally "hidden" from others. Rather than fearing the varying reactions to unpredictable events, I came to embrace them as representative of my epistemological and theoretical viewpoint and added to the richness of data. These ethnographic methods are informed by, and entwined within, the methodological practice of ethnography and determined by my philosophical commitments.

3.5 Ethnography in healthcare

The term ethnography comes from the Greek words ethnos (*people*) and graphei (*to write*) (Reeves et al. 2013), and in its earliest form dates to antiquity where Greeks and Romans described cultures they encountered on their travels (Holloway and Galvin 2017). Modern ethnography gained popularity around the 19th century within the discipline of Anthropology (the study of behaviours and cultural practices within a society), ethnography was the descriptive account of an anthropological study, usually located outside of western societies (Eriksen 2004), and was seen somewhat as a rite of passage for Anthropologists conducting fieldwork (Hammersley and Atkinson 2019). Early Anthropological based ethnographic fieldwork was mostly undertaken outside of the West and required researchers to spend extended periods of time within unknown communities in order to observe and interpret their way of life. During the 20th century however ethnography became more popular in western sociological studies, and it was adopted as a methodology by other social sciences such as educational research (Hammersley 2006). As urbanisation grew so did the interest on the social effect of urban ecology, industry and economic growth, also consumerism became of interest and during the latter part of the 20th century ethnography started to be used by psychologists and culturists in order to understand consumer audiences (Timothy 2009). The use of ethnography across different disciplines and in different context has impacted its indistinct definition as it has evolved not only over time, but also across contexts.

Ethnographies in healthcare developed as part of a branch of medical anthropology which looked to describe health believes and practices in different cultures (Rashid et al 2015). Healthcare research has historically been strongly reliant on quantitative approaches (Goodson and Vassar 2011; Tariq and Woodman 2013). Evidence-based practice has emerged based largely on quantitative studies with randomised controlled trials (RCTs) being advocated as gold standard data (Portney 2020). Nevertheless, over the last two decades cultural shifts and focus on patient experiences has seen a significant increase in the use of qualitative methodologies (Pope and Mays 2009; Oppenauer et al. 2019; Mays and Pope 2020).

Early ethnographies in medical settings predominantly focused on the socialisation of professions, power relationships and hierarchical societies. Goffman (1961) famously studied the world of institutionalised patients in a Psychiatric Hospital, his aim was to understand how they lived their lives from their perspective and understand how that was similar or different to others outside of that institution. Goffman (1961) proposed the concept of a ‘total institution’ where the usual social rules and constructs in society did not apply.

He describes how patients enter the institutions with an understanding of their own identity constructed through their social world, and how this is lost through processes which homogenise, marginalise and deprive them of their sense of self. Goffman’s concept was that these institutions compulsorily reconstructed a patient’s identity.

The public opinion of institutions at this time would have largely been shaped by their healthcare experiences based in the previous years of post war Britain and the early days of the NHS. Prior to the 1930s poorhouses, later known as workhouses, provided much of the institutionalised care for ‘the old and infirm’ (Brown 2016). When local Government took control of these instructions in the 1930s, older people were considered inferior and of less medical interest and their care was kept to these former workhouse buildings with inferior conditions, with younger people being cared for in the main Hospitals (Barton and Mulley 2003). Latterly most of these workhouses were developed into Community and Day Hospitals as was the one under study. Although most of the patients using the current Day Hospital would have been very young when these changes took place, they are likely to have been influenced by the tales of the workhouse poor from their parents and grandparents, some of which were recalled to me during my observations. This felt significant as the homogenisation and marginalisation that was felt by people within healthcare institutions over half a century ago was still remembered and referred to today.

Although ethnography is not widely used in healthcare research, it has been advocated by a few authors for the ability to facilitate accessing health beliefs and practices, subsequently aiding understanding of behaviour associated with health and illness (Savage 2000; van der Geest and Finkler 2004). Savage (2000) highlights that ethnography has become more valuable within healthcare as patients’ views and experiences of illness and services are recognised as imperative to progression. Because of the nature and depth of data created this approach can uncover tacit actions, work ethics and/or skills that may otherwise go unnoticed but potentially be fundamental to the concept under question. Ethnography has been used for example, to explore how compassion is enacted and facilitated (Sima et al. 2017), how health technology supports safety in intensive care (Leslie et al. 2017) and how stroke consultations were conducted (Bridgwood et al. 2020).

3.6 Ethnographic strengths and limitations

In relation to my study ethnography offers the opportunity to explore in depth the culture regarding frailty within the Day Hospital both through the understanding of the organisation of health provision but also through the understanding of patient’s experiences. It allowed for cultural processes to be uncovered and voiced in ways that may otherwise be drowned out by cultures outside of its own. Identifying differences between what people say and what they do and understanding why they may be different calls for approaches which can address complexity (Savage 2000). In this study ethnography has enabled me to explore and identify the ways in which formal structures such as the comprehensive assessments and treatment plans are influenced by informal systems created by the views, perspective and interactions of individual actors and groups within the Day Hospital. Van der Geest and Finkler (2004) highlight the usefulness of this, particularly within a hospital environment, as hospitals often possess dominant cultures that are difficult to identify from surface impressions.

As with all research approaches ethnography has limitations. In this study participant observation has raised some interesting ethical issues in relation to consent when observing, especially as I was observing potentially vulnerable groups of people who may be at risk of cultural hierarchy and power inequalities. A detailed explanation of how this was managed is given in the following chapters. Most ethnographies are also time intensive in terms of trust building, data collection and analysis, and can be mentally challenging for the researcher as they may unravel and navigate their own beliefs and cultural practices within this differing context (O'Reilly 2009). Another limitation is that ethnography does not lead to traditional generalisability because the findings are based on cultural responses so the outcomes cannot be applied in a different setting (Savage 2000; Goodson and Vassar 2011). As previously discussed, debates regarding the importance of generalisation in ethnographic research are based on differing philosophical outlooks. However, it is possible to co-produce findings that possess transferability regarding practices and beliefs. If the context of data creation and the setting is described in enough detail readers can see how the findings may or may not be relevant to their own settings.

A further consideration is that of subjectivity, my interpretation of the cultural experience will be different from someone else's. This is explained in greater detail in section 3.8 on positionality. You cannot remove subjectivity from ethnography, nor should you, as the data are collected through the researcher and co-constructed with the participants. In order to add trustworthiness to the data I have outlined techniques in the following chapters, such as the use of a reflective diary, memos and notarisations on the fieldnotes, which acknowledges and takes in to account these influences.

3.7 Exploring the culture of frailty and identity through ethnography

I suggest that ethnographic enquiry is central to understanding the complexities of cultural norms and enacted experiences within the Day Hospital. It affords access to both apparent and subtle interactions, cultural norms and belief systems which may not be accessed or observed by other methods. Ethnography has enabled me to access knowledge about belief systems and cultural norms which are less explicit e.g. information that participants may deem *unimportant* or *irrelevant* if interviewed.

Differential power relationships permeate much of the daily lives of older people, social interactions and experiences within healthcare practice. Ethnography held space and time for these relationships to be heard, unravelled and understood even when interactions were episodic in nature and relationships built over several months. Through prolonged immersion and engagement with the culture I was able to build and establish mutually trusting relationships which enabled more humanised interactions, processes and expressions to be seen, heard and noted.

3.8 Positionality: *insider or outsider*? That is the question

As individuals we are positioned in life, and our positionality is based upon our range of past and present experiences and the feelings and values we attribute to them. In research positionality describes the position that a researcher adopts in relation to a specific project (Savin-Baden and Major 2012), as well as how their ontological and epistemological assumptions influence their view of the world. It is important for researchers to clarify their position, arguably more so for ethnographers, as they often enter a community and culture different to their own, identifying as “outsiders” to the research (Kerstetter 2012). Our positionality could then be described as an output of our ontological and epistemological notions, how we approach and engage in a situation. From my epistemological viewpoint outlined earlier in this chapter, I discuss positionality not as a fixed concept, but one that can move, change and be moulded by ourselves and those around us.

Researchers are positioned, whether they actively engage and acknowledge their positionality or not, and their studies and outputs will be influenced by this position (Berger 2013). In ethnography the collaboration between the researcher and social actors in the field is ethically and functionally significant, the co-construction of trustworthy data is largely dependent on the strength of collaboration and the acknowledgement and navigation around differences and similarities between the two parties (Chereni 2014; Kirner and Mills 2019). Engaging in ethnographic research opens a shared space and as such the identities of the researcher and the researched will impact its process (Bourke 2014). Within this space the researcher and the researched hold dynamic and integrated roles in order to co-construct the data. The researcher, the ‘outsider’ is seeking the world from the perspective of the researched, the “insider”. This insider/outsider differential forces us to examine our own assumptions, commonalities and differences before, during and after the field and shape our fluid position as such. My claim through my experience in the field is that outsider/insider roles are not fixed, static concepts. At numerous points throughout the study my insider or outsiderness was negotiated and constructed in conjunction with the Day Hospital community. My position was fluid, the extended periods in the field meant that I became entwined within the lives of others and this called for the constant negotiation of these relationships (Cunliffe and Karunanayake 2013; Hammersley 2019). I suggest that the roles and identities of those within this study, including myself are shaped by each other and this needs to be acknowledged and recognised.

Positioning myself in relation to those in the Day Hospital community was complex, I found that I positioned myself and was positioned by others in several contexts. I am a nurse pursing a clinical PhD and career as a clinical academic, a role which itself contains complex identities (Corness-Parr 2019). Throughout the subsequent methods and findings chapters I touch upon some of the ways in which people treated me. Some appeared to hold me in high regard clinically and academically, and at times I found myself ‘playing up’ to these appointed roles. Nevertheless, my positionality was not only explained through these features, I have personal experiences and contexts which shape my position and affected the scope of my outsiderness. I am a white, 30 something (nearly 40), single parent female with high social and cultural capital but relative economic poverty. My personal experiences and interests in identity formation have significantly influenced the development of relationships and roles both within and outside of this study.

The study originated as part of a joint funded studentship between the hospital trust and Bournemouth University with an overarching concept of exploring how a Day Hospital meets the needs of frail older people. The specific details of the study were founded in my clinical experience working with older people over the last decade who expressed the challenges they faced managing their changing identity as they aged. I also acknowledge that I had personally been challenged by issues related to understanding my own identity having been adopted by my grandparents and raised in a family with a large generational gap. I struggled with what I found to be a confusing identity as a daughter, granddaughter and more recently a carer for my aging parents. This caring role has occurred much earlier than most of my peers whose parents are mostly in their 60s. I acknowledge that this search for understanding of my own identity meaningfully impacts my nursing practice and the desire to ensure patients’ identity needs are supported as well as gaining a greater insight into the identity challenges faced by others. The experience of caring for my Mum, who sadly died during the first year of this study, I feel significantly contributed to my perspective in the early stages of the ethnography. Issues with her self-image and frailty directly impacted upon her participation in rehabilitation and the way she felt about herself in relation to her condition. Although I may be considered an outsider from the perspective of an older person, I can empathise with some of their experiences. In fact, I feel that being considered an outsider by the older people, enabled me to obtain a deeper understanding of their perspectives. I was seen as separate to the staff and as such social insights were gained which I feel would not have been shared with staff members. Outside of this study I am still a carer for my Dad who is now 90 and have faced many of the difficulties and joys that this brings, I hold a shared commonality with the relatives in the Day Hospital sharing similarities and insights with their worlds. Additionally, my role as a nurse and experience working with older people seemed advantageous in terms of my ability to quickly establish myself within the therapy team at the Day Hospital and I felt this assisted the process of collecting observational data.

Although this can be challenging at times as I move between different roles, I feel these experiences, and importantly acknowledgement of them, has led to more enriched interactions. Nonetheless I acknowledge that these advantages can also pose as disadvantages. Bonner and Tolhurst (2002) discuss how familiarity with the processes and practices within the group may mean that reasons behind them are overlooked or assumed. I have been challenged at times to manage the multiple identities of nurse, researcher and carer/relative. When observing and recording data from fellow nurses and therapists my ‘nurse self’ wanted to sometimes protect them from their own words, yet my ‘research self’ wanted to investigate and probe further or challenge the use of particular practices. As a nurse there were times that I felt I understood why another nurse may say or do a certain thing, or assumed I knew what someone was trying to say because I had experienced similar feelings and emotions. Reflexivity, or understanding the relationship between my belief systems and the research, is a key concept when trying to minimise these potential issues as well as elucidating and acknowledging their impact on the research (Underwood et al. 2010). I kept a reflective diary to assist with this, which became an invaluable place for me to examine my thoughts, feelings and emotions surrounding events and interactions, and their potential impact on my interpretations of the research. The process of which I will share in subsequent chapters.

In this study I looked to understanding how identity was understood, constructed and supported. As I moved through the research process observing roles that both individuals and collectives enacted within the Day Hospital, I navigated the insider/outsider continuum. My position was fluid and dynamic, many times I reflected and debated where I stood. I have come to understand that the dynamic between myself as researcher and the researched or indeed as listener and informer is an integral part of the data, the co-construction of which is not an objective truth, but a representation of my interpretation of these interactions and observations. Truth in this sense can only be achieved through the extent to which my interpretations correspond to how actors construct and interpret their own realities.

Chapter 4 Ethnography methods: In the field

In the previous chapter I explained my methodological framework and the steps I took to conceptually prepare for this study. Over the next three chapters I will reflectively outline how I planned the more practical elements of the study, the fieldwork methods adopted, and the process of data analysis undertaken both within and after the field. Ethnographic methodology and methods are closely entwinned as previously described. Ethnographic methodology is founded in principles of deep enquiry and explanation of a cultural world (Fetterman 2019). The predominant method used to do this, participant observation, has to be carried out with these methodological ways of thinking in mind. Using research methods to observe a community, does not qualify a study as ethnographic, the qualification lies in how the researcher was thinking and their methodology, when using the methods (Waring and Jones 2016). Because of this interwoven relationship between methodology and method I spent considerable time deciding on how best to present these chapters within this thesis. I have designed this chapter perhaps in a less formal structure than may be expected in some medical or health texts, I felt this necessary not only to remain faithful to the reporting practices within ethnographic work, but also to convey the reflexive nature and journey of the ethnographic process, and to communicate a sense of methodological thinking within the methods used.

In the first of these method chapters I provide an overview of the study, the study setting and participants, and describe the involvement of patients, relatives, staff and volunteers in its planning. I reflect upon the rationales and ethical considerations of the methods used and how deliberation of these elements formed the day to day workings whilst collecting data and my position as the researcher. In chapters 5 and 6 I detail the processes of recruitment, data collection and analysis in each phase of the study, giving explanation and justification to techniques used and discuss the importance of trustworthiness in ethnographic research. Throughout these chapters I reflect upon my position in the field as an embodied research agent and how acknowledgement and reflexivity around this shaped the methods used.

4.1 Study design: Study overview

As discussed in chapter 3, using ethnography as a means of inquiry requires the reconstruction of a story about individuals and events as they occur naturally (LeCompte and Schensul 2010; Fetterman 2019). In the previous chapter I discussed the relationship between my chosen methodological framework of ethnography, my epistemological lens and how I developed the research questions that guided this inquiry. Having developed this methodological base and identified the population of people with frailty I moved on to planning how the study would be conducted, the research methods, data collection and analysis plan. The methods I chose needed to enable me to understand how individuals and groups within the Day Hospital interpret their world and permit me to observe what people do and why they do it (Kirner and Mills 2019).

In order to provide a contextualised understanding of the created culture of identity within the Day Hospital I decided on a two-phase approach. During the first phase I collected data via observations and participant observation spanning a period of nine months starting in November 2017. The main aim of this phase was to explore and understand the organisation structure and workplace interactions regarding frailty within the Day Hospital, and to appreciate how identities were understood and constructed within this setting. During phase 2 of the study I used focus groups to elicit a deeper understanding of the themes identified from the analysis of phase 1 and add credibility to the findings (LeCompte and Schensul 2010). The focus groups were planned and conducted over a six-month period starting in August 2018, and in combination with the emergent themes and findings from phase 1 identified cultural underpinnings of how sense of self-identity is acknowledged, understood and constructed for older people with frailty within the Day Hospital and the positive processes which support this. Figure 3 outlines each phase with respective data collection methods and timeframes.

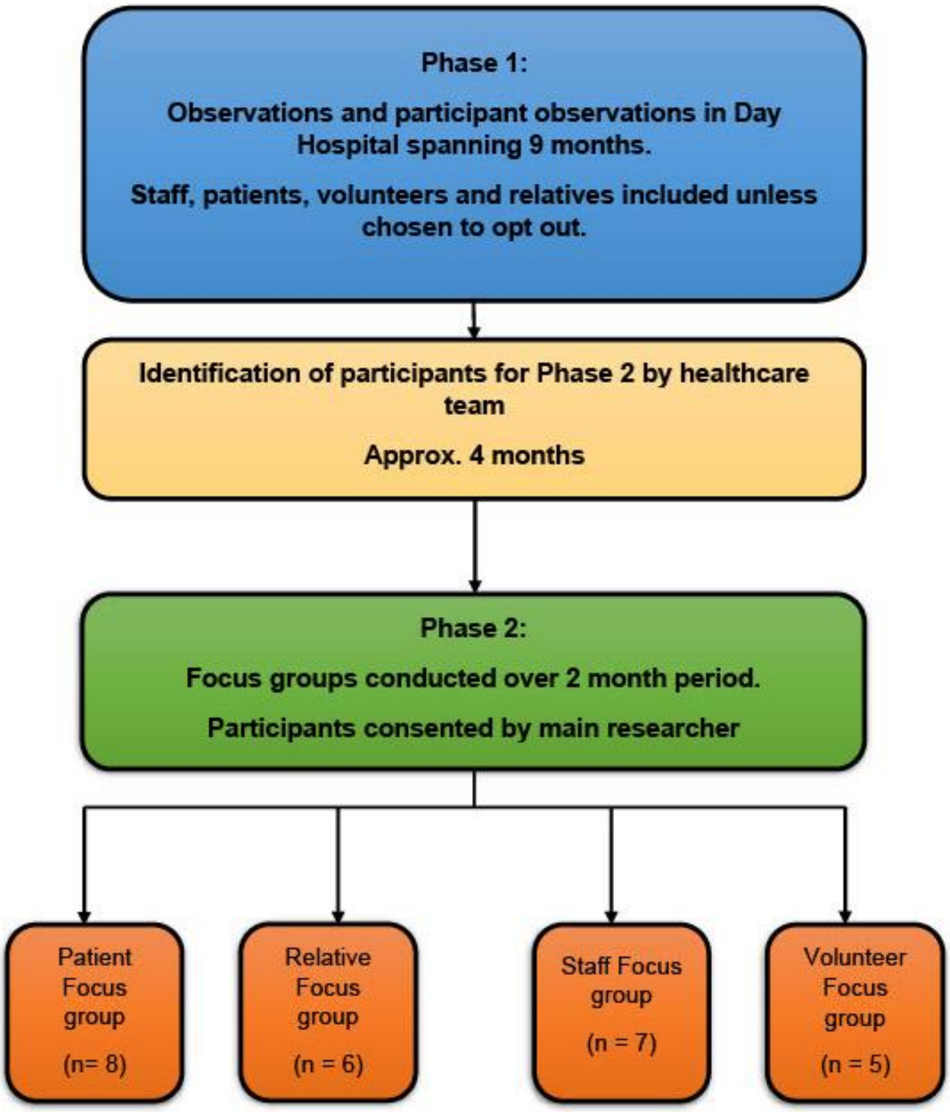


Figure 3: Study flow chart

4.2 Setting the Scene: study setting

4.2.1 Day Hospital: *The field*

The notion of '*field*' and '*field work'* is strongly grounded in ethnography. The field is simply the setting in which the research tasks or '*fieldwork*' is carried out (LeCompte and Schensul 2010; McGarry and Mannik 2017; Fetterman 2019), in this case a Day Hospital unit of a medium sized NHS University Hospital in the

South of England. The hospital provides healthcare for a catchment population of around 550,000 and the Day Hospital provides specialist treatment and expertise in rehabilitation predominantly for older people. The care of older people is a core focus of work in this geographical location as the percentage of those aged over 65 years is 33.2%, well above the 17.7% national average for the UK (Office for National Statistics 2018a), and it has the highest population of people over 85 years old in the United Kingdom at 5.6% (Age UK 2018). The Day Hospital is situated on a satellite site approximately three miles from the main hospital and has been largely redeveloped over the last few years. Except for the Palliative care unit, it is now an outpatient site with a focus on rehabilitation. The Day Hospital was established in 1970 with a team of Geriatricians, Occupational Therapists, Physiotherapists, Nurses and Therapy Assistants specialising in the rehabilitation of the older person.

Patients are referred to the service from a variety of places including the main inpatient hospital, GPs, Community Matrons, Community Rehabilitation Services and Virtual ward/Community MDTs. Referrals are triaged by senior therapists or nurses daily and are accepted for people who require assessment and support with personal activities of daily living due to their health condition. These can range from washing and dressing to higher executive functioning such as managing medications and finances. Although frailty itself is not a criteria for referral, it is widely accepted that those attending the Day Hospital are on the frailty spectrum. This is corroborated by the Trusts use of the Clinical frailty scale (Rockwood et al 2005) to determine a person’s level of frailty. Within this scale those that would meet the criteria for the Day Hospital would be classified as, at the least, mildly frail. The vast array of ways that patients can be referred to the service also means that I had access to patients at different stages in their healthcare journey i.e. after an acute illness or those needing on-going community input.

4.2.2 Day Hospital organisational structure.

Figure 4 outlines the organisational structure within the Day Hospital. The overall managerial responsibility for the Day Hospital is attributed to a service manager who is a nurse, the day to day running of the Day Hospital is managed by two clinical managers a physiotherapist and a nurse. The service manager predominantly focuses her time on high level strategic management decisions, integration of patient flow across the trust and managing the links with other community services, whilst the clinical managers generally deal with complex patient needs, staff welfare, staff rotas and daily patient flow through the unit.

These managers serve a team of therapists, nurses, and therapy assistants as well as administrative support services. Most of the team are permanent staff (i.e. not on clinical rotation), many of whom have worked within the unit for 10 or more years. These staff are all trained to carry out the initial indepth assessments on patients at their first appointment. Some also run specialist clinics within the Day Hospital such as the vestibular clinic and the Functional Electrical Stimulation clinic.

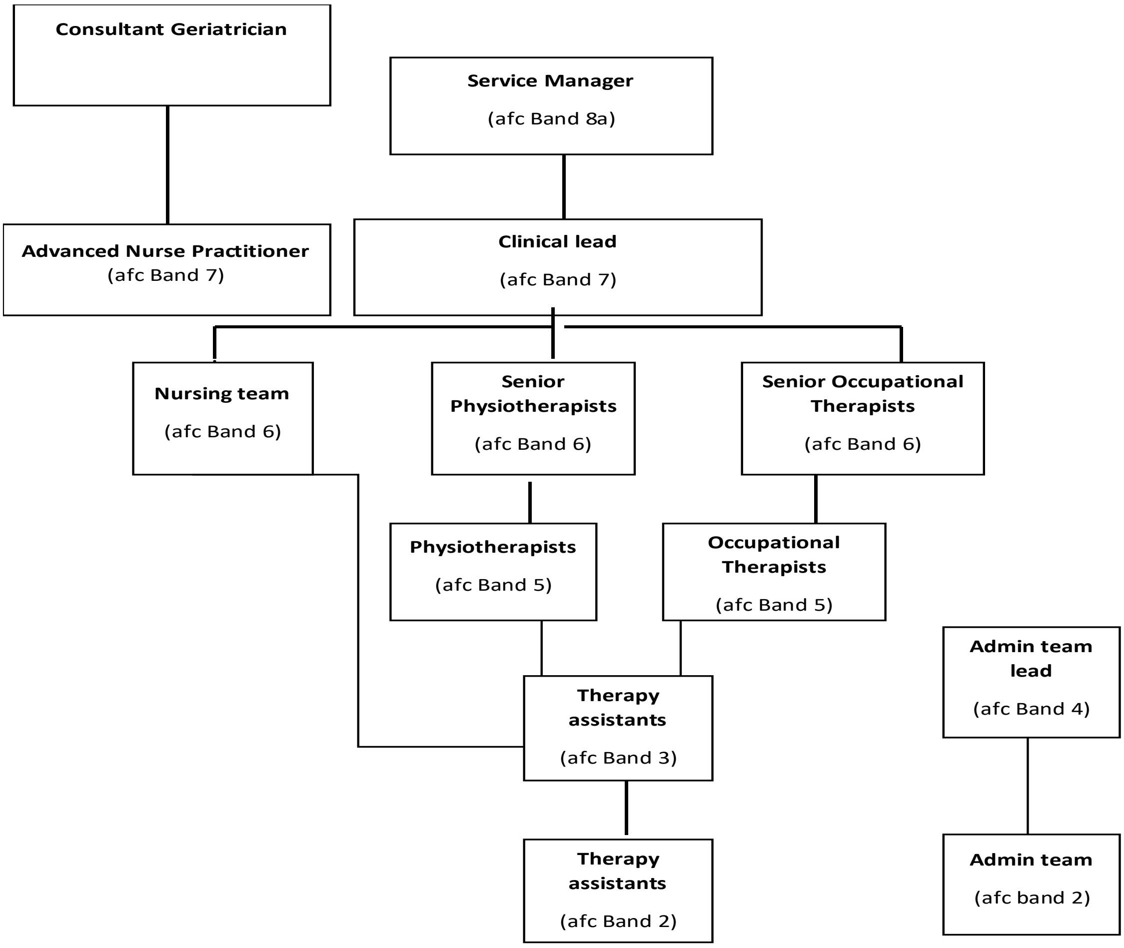


Figure 4 Organisational structure of the Day Hospital

More junior, rotational therapists and therapy assistants implement the care and treatment plans generated by the initial assessment processes. Additionally, the Day Hospital is supported by several volunteers who prepare and serve refreshments for the patients and relatives whilst they wait for their appointments.

4.3 Planning the study

The initial idea and funding for this study came from a collaboration between Bournemouth University and the hospital trust. Despite a decline in Day Hospitals throughout the country (Parker et al. 2009), this Day Hospital maintained and developed innovative services for older people with frailty and receive positive feedback from patients. A Cochrane review highlighted that further research was needed to determine the effectiveness of Day Hospital services, and that the views of those that used them were seldom heard (Brown et al. 2015). The trust wanted to understand which positive processes underpinned the work that they are providing and understand how those with frailty have their needs met within the service. With this brief in mind I began to research the concept and treatment of frailty and found that there was a paucity of research surrounding the experience of navigating healthcare services whilst living with frailty, and how identity is understood and constructed within this system. As previously explained, I felt that the processes within ethnography would enable the voices of those with frailty to be heard as well as giving insight to the construction of identities.

Having worked in a clinical environment for much of my career, where many processes and procedures are often inflexible and prescriptive, the apparent fluidity and, at times, seemingly unstructured processes of ethnography was initially daunting. Traditionally medicine is founded on quantitative science, where focus is on control, in contrast qualitative ethnography requires adaptability, fluidity and change and focuses on relationships and processional events (Goodson and Vassar 2011). As a novice researcher, but experienced clinician, I had to be open to the possibility of change in any plans that I made and that changes and spaces that emerged and developed within these plans were important and essential data sources. This did not mean that my ethnography was unstructured, as a doctoral project I had time and financial constraints to consider. Additionally, there were several complex ethical issues that I needed to contemplate and plan for accordingly particularly working within an NHS environment (see section 4.4).

Above all it was important to me that the study felt relevant to the people I looked to observe, not only for the potential impact of the findings on future care provision, but I felt that a sense of relevance would also be imperative if I were to be effectively accepted in to the Day Hospital community. Many people with frailty may have already developed long term relationships with healthcare workers and have long histories of using healthcare services, I was mindful that for me to fit into the culture within the Day Hospital participants would need to feel that the study was valuable and meaningful and that there was some reciprocity in the relationship with them. Because of this, from the early development stages, staff, volunteers, patients and their relatives were involved in the planning of the study.

4.3.1 Patient and public planning involvement

Patients and public involvement (PPI) is a recognised and expected part of the design and development of healthcare research (Newhouse et al. 2017; Evans et al. 2019). The Day Hospital has an established patient and public feedback system with at least annual discussion groups which patients, carers and relatives can attend. At these groups' patients are asked to give feedback on service development ideas and suggestions for service improvement. The initial plans for this study were presented to one of these discussion groups, facilitated by the Day Hospital focus group co-ordinator and supported by the Trust's patient engagement coordinator. Feedback was gained on several areas including;

- Discussing the topic of frailty and identity, and the relevance of this for this age group.
- Discussing how best to involve people at each stage of the research, so that people feel engaged in a meaningful way.
- How the group felt about a proposed opt-out system of observational consent.

- Discussion on how they would like the focus groups in the main study to be run i.e. with patients and relatives combined or separately for example.

The group felt that the topic of identity and frailty was important and relevant as they shared personal experiences where they, their friends and family had struggled with their sense of self-identity as they aged. They discussed the data collection method of participant observation at length and felt that this was a vitally important part of the project. The group felt that if people are not observing what is "truly" happening then there is no way to understand it and progress things. Although some members of the group felt that there wasn't a need for information posters in the observation phase, they agreed collectively that some people may be upset if they were observed and there was no information at all. They decided that posters explaining that an observational study was taking place and that they could 'opt-out' would be acceptable as well as a short sentence on the bottom of the appointment letter.

The sentence that was suggested was.

"The Day Hospital is taking part in an observational research project. If you do not wish to be observed, please tell a member of staff".

Furthermore, I felt that a study information sheet could also be given at the initial assessment of each patient coming to the Day Hospital which would outline the key aspects of the study.

When discussing collecting data via focus groups, the PPI group felt that patients and relatives should have separate groups so that it would give the opportunity for sensitive topics to be discussed around identity. There were two married couples in the PPI group and they both felt that they would benefit from being given opportunity to speak freely without risk of upsetting their partner. They felt this was important as they had recognised changes in their partner's sense of self-identity as they aged. The group also reviewed the patient participation sheet, overall, they felt it was clearly written and understood the information given. Generally, there was positive regard for the study and the group felt it was very interesting and worthwhile. Following their discussion, the above suggestions were implemented within the study protocol (Appendix 1).

4.3.2 Staff and volunteers planning involvement

The concept of the study was initially agreed by the Day Hospital management and it was explained to the staff that a study would be conducted. After this I attended two staff team meetings to introduce myself, explain my ideas and discuss my proposals. The staff felt that the topic was valid and appeared keen to be involved. We discussed the concept of observations and I made it clear that participation in the study would be voluntary. I was mindful of potential power balances between the staff and the management and that staff didn’t feel pressured to participate. Basic principles of informed consent lay the foundation for participants whether staff or others to not feel coerced or unduly influence (Bracken-Roche et al. 2017), Resnik (2016) highlights that this coercion can be very subtle and implicit in a work environment, where people may feel obliged to participate through fear of ‘upsetting management’. To try and minimise the risk of this I asked the management if I could present the study to the staff rather than them, and that they did not initially get involved in discussing participation in it with staff. Where the researcher links directly with the prospective participants is considered to be the lowest potential for coercion as I had little or no relationship with the staff (Festinger et al. 2011; Resnik 2016). Once I had designed the participant information sheets (PIS) I also presented these to several staff and volunteers to read and comment on. They all felt that the information was easy to understand, and many inferred they would like to participate.

4.4 Ethical considerations

When undertaking research that involves an NHS setting several ethical approvals are required. These include approval for the study from the Health Research Authority (HRA) and National Research Ethics Committee (REC). The HRA is the overriding body that provides approval for research within the NHS, whilst the REC provides an opinion to the HRA on whether they consider the aim and methods of the research to be ethical. Their focus is the participants and they are entirely independent from the sponsors of the study, this enables them to ensure that the research is reasonable and principled (Health Research Authority 2017). At an early stage I recognised that there may be challenges in obtaining ethical approval for this study, I was looking to access and observe a population frequently deemed as vulnerable in a clinical setting, using a methodology that is not common to health research within the NHS. Much of the ethics and regulation around health research focusses on making the research processes explicit to the participants, however as previously explained, in an ethnography, it is difficult to anticipate a number of elements of the research process as much of it is inductive, open and fluid, with the process being refined over time whilst in the field (McGarry and Mannik 2017; Fetterman 2019). One subject that can be ethically contentious therefore is issues around consent and in particular, for this study, ‘opt out’ rather than ‘opt-in’ consent for phase 1.

4.4.1 Informed Consent

I felt it was important to discuss the issues around consent in ethnography early in this chapter as it is complex and shaped the way in which the data were collected. The notion of informed consent in both medicine and research has changed significantly in the last century (Wolf et al. 2018). Informed consent enables autonomy, transparency and integrity (Beauchamp and Childress 2001). A number of high profile atrocities including the Nuremburg Trials in the mid 1940’s (Roland 2012) and more recently the Tuskegee Study, which ended in 1972 (Gray 2002), were pivotal in changing the emphasis on regulatory compliance with informed consent.

In healthcare, obtaining informed consent is purported as best practice before any intervention, with particular importance placed on ensuring populations deemed to be vulnerable are afforded the same treatment regarding consent as other populations (Beauchamp and Childress 2001; NHS 2019b). This is relevant to this study for two main reasons; firstly, by the nature of their condition and its potential impact on functionality, older people with frailty are generally considered to be vulnerable (Slaets 2006; van der Meide et al. 2014). Secondly, to understand interactions and the culture they construct requires observation of the population. Medicine has historically been paternalistic in decision processes and power balances particularly in populations that are deemed vulnerable (Eliassen 2016; Scholz et al. 2018). This means that interactions between clinician and patient are often shaped by social expectations, with actual or perceived power differentials, potentially impacting upon the reactions and responses from both parties. In order to gain a sense of natural interactions in the setting, I needed to employ techniques which would minimise this power differential and support the natural flow of the interaction. This meant that informed consent prior to every observation was neither practical nor methodologically sound.

Most healthcare research relies on participants ‘opting in’ to a study. The ‘opt-in’ method of consent requires a participant to sign up to the research and for their data to be used. However, Spradley (2016) argues that for population research such as ethnography, this means that only the most active are likely to take steps to ‘opt-in’ and therefore a large section of the potential study population might be missed. Moreover, the foundations of the traditional informed consent process and opting in, are firmly rooted in clinical trials and biomedical experiments which are fundamentally different to ethnography (Dankar et al. 2019; Fetterman 2019). Informed consent was developed from biomedical experiments where episodic interactions and intervention with researchers lent themselves to this type of consent as the interventions and interactions could and needed to be planned and anticipated (Gupta 2013). In contrast to these types of episodic events my aim was to immerse myself into the environment so as to be accepted as part of the community over a long period of time (Fetterman 2019; Kirner and Mills 2019). This mean that rather than episodic consent, consent to my presence was negotiated and renegotiated over time as the relationships developed between myself and the participants (Murphy and Dingwall 2007). The course of an ethnography cannot be anticipated in the same way as an experiment, and therefore it is difficult to apply the same consenting framework (Parker 2007). To overcome these methodological dilemmas of power differentials and inclusivity, I chose to use an opt-out consent process during phase 1, the specific detail of which I highlight in the following chapter.

4.4.2 Ethical and legislative approvals

The study was reviewed and given favourable opinion on 23rd August 2017 by South Central Berkshire REC ethics no 17/SC/0367 subject to some minor amendments shown in (Appendix 2). Prior to the REC board consideration, I had proposed that the staff and volunteers would opt-in to phase 1, I did this as I felt that some ‘traditional’ consent processes would be ethically more acceptable to the REC. I was fortunate however to come before a REC panel who understood the methodological implications better than me at this stage, it was they who suggested the opt-out consent was methodologically appropriate and ethical, and should be used by all participants, staff and patients alike, to provide equity. Additionally, they asked me to include the wording ‘*how you feel about yourself*’ after the word identity on the poster, as they felt this would help with understanding of the term. Subsequently, the study was approved by the HRA (Appendix 3) and local trust research directorate.

4.4.3 Assessment and management of emotional distress

4.4.3.1 Emotional distress to the researcher

The exploration of topics that may be considered sensitive such as sense of self-identity and long-term health conditions may bring greater possibility of emotional distress to both participants and the researcher (Brewer 2012). As I recounted in chapter 3 I spent much of my time within the field and thereafter balancing my own positionality and emotional equilibrium. Many of the interactions, stories and observations resonated deeply with my own position as a daughter and carer of older parents, who both developed frailty during this period. I was the researcher but could just as easily have been a participant, and as a human, immersed in the study of a social world, social and emotional connections and involvement inevitably developed (Johnson 2009). Both my supervisors and I recognised at an early stage that we needed to put strategies in place to assist the processing of emotional reactions and/or distress. We decided that we would hold supervisory meetings every other week during my data collection period, these would give me the opportunity to discuss any challenges or concerns I faced at the time, as well as processing the information already collected and finding a direction to move forward. This strategy worked well for me, these supervisory sessions often became pastoral in nature and held space for me to reflexively consider my interactions and personal emotions. Additionally, we had a plan in place for external support from the University counsellor, if the support needed moved beyond the scope of the supervisory team, as it is expected that any qualitative research may trigger emotional responses in researchers (Denzin and Lincoln 2011). However, this was not needed.

4.4.3.2 Emotional distress to participants

I have several years of experience as a nurse working with older people and substantial experience discussing sensitive topics. Every effort was made to reduce the chance of distress to participants by approaching the interactions and interviews in a humanised way and using sensitive dialogue. For example, there were times that participants became visibly upset by talking about their partner or child who had died or through frustration at their lack of physical functionality. If this happened, I would check that the person wanted to continue the conversation, if they did, I listened carefully to what they were telling me, when they finished if their distress appeared unresolved, I would sensitively ask the person if they wanted any further support from one of the clinicians regarding these issues, if they agreed then I would let a member of their healthcare team know so they could support them further or signpost them appropriately. During the focus group discussions, I also had a note-taker present who was able to offer immediate personal support to anyone that needed it in the group. However, none of the participants accessed this additional support during the study.

4.4.3.3 Reportable practice

During the study there was a possibility that I may have been informed of or observed unsafe practices. As a registered nurse I had a legal and professional duty of care to ensure the reasonable, foreseeable safety of patients and public (Nursing & Midwifery Council 2015). I knew that if I were informed of or witnessed practice that would be deemed reportable i.e. gross malpractice, patient safety, financial impropriety, or any other serious risks to patients, public or staff, I would need to follow the trust policy reporting procedure. I needed to balance my nursing identity with my researcher’s identity. I found that things may have been said or done that were different to how I would have worked clinically but I didn’t encounter any reportable incidents. I used my supervision to support me through these data collection phases, off load, reflect and regroup my thoughts and feelings. My supervisors are registered healthcare professionals and I feel this helped me to bring perspective to situations where I may have felt overwhelmed by the data. The PIS informed readers of my obligation to report any unsafe practices that may be raised during the study and I also made this clear during my meetings with the staff before the study started.

4.4.4 General Data Protection Regulation (GDPR) and patient confidentiality

GDPR is a regulation based on European law that aims to give individuals autonomy over their personal data. GDPR came in to force in May 2018 during the first phase of the study. I had originally based my data protection plans on the Data Protection Act 1998 (Data Protection Act 1998, Bournemouth University’s Code of Good research Practice 2017 and protocols for data management with regards to the collection, storage, processing and disclosure of personal information. Prior to recruitment in phase 2, I added additional GDPR information to the PIS and consent form that outlined the parameters of the data collected (Appendix 4). Any information and data gathered during the study is currently held on a Bournemouth University password protected server and will be stored securely following the submission of this thesis for a period of five years.

4.4.4.1 Anonymity and confidentiality

Central to ethical research practice is the anonymity and confidentiality of participants (Crow and Wiles 2008). In most research literature the terms anonymity and confidentiality are used in conjunction and sometimes interchangeably (Saunders et al. 2015). Surmiak (2018) and Saunders et al (2015) suggest that confidentiality is really a generic term, one of hiding information, and anonymity i.e. keeping participants identities hidden, is one form of confidentiality. In research the aim is to produce findings based on the data collected, confidentiality is therefore unobtainable in the sense that the information provided, and observations made will be utilised for the basis of the findings. They also argue that anonymity in the true sense of the word is an unrealistic goal in most qualitative research, as commonly the researcher will be working with and know the identities of the participants. Indeed, there appears to be much debate regarding the process and ethics surrounding anonymity in qualitative research, of which is outside the scope of this thesis, however there are a few points that I would like to make regarding my experience and choices in this area. I acknowledge that most ethical guidance recommends anonymising participants identities (Surmiak 2018), however there is an alternate view that routinely anonymising qualitative data is paternalistic and disempowering to the research participants themselves (Giordano et al. 2007). I felt this was relevant to briefly mention here as, quite unexpectedly, many of the patients that participated in the focus groups, specifically commented on the fact that they were happy if their identity was not anonymised and hidden. In many ways I sensed they felt it was a way to share their story.

I did go on to anonymise the data as best I could, by this I mean that it was not as straight forward as changing people’s names but a more thorough process where I needed to consider other potentially identifying details. It became a balancing act between maximising the anonymity of the participants against preserving the integrity of the data (Saunders et al. 2015). I am quite a visual person and generally feel visual methods of data can add rich content to research, however I decided against including photographs of participants in the data and only took photographs of specific objects or areas which I felt would be generally anonymous to anyone other than those that were familiar with the space, but significant in terms of their richness of visual description (Crow and Wiles 2008). I felt the most efficient way to anonymise the data would be to do so in the field during the inscription and transcribing process which I outline in detail in the next chapter. During phase 1, I predominantly used visual descriptors such as patient with pink cardigan or red shoes, I found that these tended to be based upon their physical appearance and things that I felt would prompt my memory when I came to expand the writings later. During this phase I quite often didn’t know the full name of someone I was observing so in many ways’ anonymity of the patients and relatives seemed relatively easy. It was not so simple though with the staff and volunteers as I quite quickly learnt their names and was conscious that through their close working conditions there was more potential for one of their colleagues recognising their identity. In these situations, I would initially use their name in inscriptions but then when transcribing and expanding the field notes would use their profession such as physio or nurse. If I was describing a feature which I felt would be particularly indicative of their identity I changed details in order to illustrate and represent the concept I was observing whilst maintaining anonymity. In this way the ethnographic writings are considered representations of a concept or action. All data were anonymised prior to sharing with others including my supervisory team.

During the focus groups in phase 2, I gave the participants pseudonyms at the transcription phase. Unlike the patients, the staff did appear more interested regarding their anonymity, which I surmised may have been related to potential concerns regarding managerial relationships.

4.5 Ethnographic data collection: the ethnographer as an embodied research instrument.

Before I describe the techniques I used to collect and analysis the data for the study, I feel it pertinent to discuss my role as the data collection instrument. Understanding the process of data collection in this study not only required understanding of how to observe and record field data, but also an appreciation of my preconceptions and values and the simultaneous need for reflexivity that this type of inquiry necessitates. Ethnographic studies look to understand cultural scenes and require the researcher to retell these scenes and produce sensory accounts of life as it occurs (Wolcott 2008; Morgan-Trimmer and Wood 2016; McGarry and Mannik 2017). These scenes can ever only be retold however, through the visual and epistemological lens of the researcher. When I refer to '*entering the field'* it is more than simply arriving at the Day Hospital with my notebook and pen; as an ethnographer going to the Day Hospital meant that I needed to leave my own work environment and institutional setting. I had to leave what was familiar to me both clinically and socially and enter another social world. Schensul and LeCompte (2013) describe the ethnographer as needing to learn what the residents of the field know, in terms of language and social rules, relationships and patterns.

Entering the field was quite challenging, initially I needed to map out the areas, I did not know where my focus would lie, other than broadly within the area of frailty and identity. The felt lack of knowledge and direction challenged me at the start, the openness of it all, the mass of what felt like a blank canvass was overwhelming. Reflecting on my early fieldnotes I can see I documented almost anything I observed. These early notes provided dense data, yet they were often complex to process and at times difficult to meaningfully interpret due to the volume of information and lack of focus. I was confronted with a relentless fear of missing something. In addition to the constant search for information relating to frailty and identity, I sought to learn the norms, rules of behaviour, language and relationships within the Day Hospital. I was very conscious that I needed to build relationships with people and be trusted in order to access the information I felt I needed. Over time however I came to realise that this openness and sense of unknowing was not only a positive but necessary attribute when undertaking ethnographic research.

As a nurse I felt relatively comfortable in the Day Hospital setting, the equipment and documentation were familiar to me as a health professional, I understood clinical terminology and I feel this afforded me an entry point to build relationships with staff members as we had a shared language. Nevertheless, initially I sensed an anxiety from those same staff, that they were being watched. In the early weeks of phase 1 a running joke started if I walked in the office and people were chatting, they would say things such as, *“oh quick she is here, look busy*” or “*shh she is here, we weren’t talking about anything”.* It always seemed to be said in a joking manner however my sense was there was a subtle message there regarding trust. I didn’t know if it was a lack of trust or my own anxiety, but to try and make sense of these experiences I employed reflexive techniques such as adding reflective commentaries and notations to field notes with relevant points for example; the atmosphere of the unit, the weather, how people appeared to feel, how I felt that day or any additional reflection I had subsequent to the observation that may or not be relevant. I also used mindfulness strategies to be present in the observation, interaction or interview, mindfulness can help attune researchers to be fully present in what they are seeing, feeling and sensing (Orellana 2019).

As the weeks progressed, I noted a shift in acceptance. The previous humorous comments stopped, people no longer appeared to notice when I walked in and indeed, I no longer needed to observe and document every movement as focuses began to develop. My hearing became attuned to multiple conversations and I concentrated on themes that began to emerge. I felt increasingly unobtrusive and accepted in the Day Hospital world. As weeks turned in to months, I found myself becoming more integrated with the group, the dynamisms of the data became more apparent and I was better able to focus observations and fieldnotes on areas that emerged as meaningful in relation to my research questions. This also brought with it a realisation that I had likely been afforded an amount of leeway in the early weeks in terms of behaviours and rituals. As I became more enveloped into the group, expectation of my attendance at social functions or to work as part of the team in certain situations was evident. I recall one time when a senior nurse ran in and told me '*I need you',* as I followed her running down the corridor asking what we were doing she informed me someone had collapsed in another area of the hospital and she needed help. We arrived to find several panicked phlebotomy staff trying to revive an unconscious patient and I worked together with the nurse to manage him clinically. Although not directly linked to my observations this experience certainly shaped my understanding of how I had become accepted as part of the team, it also allowed me to identify that my research skills were stronger as I recognised how I was subconsciously noting the language the nurse used with the patient and family and her mannerisms to deal with the situation. There was evidence of reciprocity in the relationships I had built, rapport and trust developed between us as information and skills were shared mutually.

Schensul and LeCompte (2013) stress the importance of reflecting not only on the meaning of experiences the researcher has, but also the personality and behavioural transformations that I was required to make due to my prior knowledge, values and beliefs. They contend that the use of reflection enables the researcher to become functionally unobtrusive in the environment allowing for others to behave more normally and therefore gain a greater insight into the culture in the Day Hospital. As I spent more time in the field I also became more reflexive, instead of solely reflecting upon observations and interactions after they occurred, I became more skilled in considering events as they happened, looking to interpret what is happening and why and appreciate my own position within that event and how this may impact upon it (Chinn 2007; Liberati et al. 2015). I also kept a reflexive journal alongside my fieldnotes where I recorded my thoughts, feelings and emotions daily, which I discuss in more depth in chapter 6.

4.5.1 Developing trusting relationships and navigating emotions: the researcher and the researched

In both phases of the study the development of trusting relationships was crucial to the quality and depth of data collected. LeCompte and Schensul (2010) describe the need to develop special kinds of friendships with participants, the development of these friendships was not taken lightly or assumed to be easy and certainly felt like an ongoing process. Although I was aware of the need to be conscious of my preconceptions when entering the field, my aim was not to detach myself in order to be objective in the data collection, rather immerse myself into another world, whilst recognising and acknowledging my own assumptions and values about the world. In the same humorous tone as they spoke when I initially came in the office, staff would ask me if I would secretly report ‘bad’ things back to management. There were times I wondered if people were testing this by doing things that were generally against the norm, but not necessarily risky, such as leaving early or taking extra lunch break, once people began to realise that these things were not fed back to management, I felt that I was more trusted.

Initially there appeared to be some confusion regarding my role at the Day Hospital, generally I referred to myself as a researcher, sometimes backing that up with *‘I’m a nurse by background’* if I felt this would create more of a connection. I tried to be personable, maintaining reciprocity of personal disclosure, and looked for shared commonalities in people that may enable growth of relationships (Orellana 2019). This ranged from previously shared professional experiences, to more personal and intimate commonalities such as relationships and children. If staff introduced me to patients, some would use my name; others would refer to me as a colleague or occasionally a researcher from the University. If they mentioned I came from the University this inevitably ensued further conversation and often intrigue with the patients. People would reminiscence about their children or grandchildren attending University and ask me what I was studying. At times this made me feel uneasy as I had preconceptions of what they may think about a PhD student, however in reality, the term PhD didn’t seem meaningful to most people and I was often referred to by patients as a student nurse which I accepted. My position was also somewhat different to other researchers, as due to the clinical nature of my doctoral degree I was required to also work as a nurse two days per week, for the first six months of the study I worked these hours within the Day Hospital, subsequently moving to an acute frailty unit. Although on these clinical days I was not acting in capacity of a researcher, I could not be disembodied from my working environment, therefore I must acknowledge that my clinical experiences will have added to my understanding of the culture, and likely led to me developing more established relationships with members of the Day Hospital community.

As in most organisational structures there was a chain of command between the frontline therapy, nursing staff and management, although this didn’t appear to be a negative hierarchal relationship, as I discuss in the findings chapter, I did find myself being drawn more towards the frontline staff. There were incidents where I was joining in *chatting* in the office and one of the managers would come in and tell us we were being too loud, I was worried initially about maintaining my relationships with these managers (gatekeepers) and started to make a point of offering research feedback at appropriate points as the project developed in order to offer more symbiosis to my presence. When carrying out observations within the public areas or therapy office I did however try to distinguish myself from a managerial role in any way. I also recognised it was important to be accepted by the management to gain insight from their perspective, it became a balancing act. I would adopt differing roles depending on the person or people I was with or observing. The more I enacted routines and integrated into the ‘*ways*’ of the unit, the more I gained access, by empathising with people and their world, sharing food and demonstrating a genuine interest in people I established more rapport. I felt trusted and an increasing desire to translate the participants truth through the data I collected.

O’Reilly (2009) suggests that trust is best build slowly and gradually over time, progressively increasing activity whilst building rapport, for me an example of empathetic rapport was most noticeable a number of months in to my observations when my Mum died and I took a few weeks off, staff sent me flowers and chocolates and all wrote individually in a card. When I returned people appeared genuinely happy to see me, said they had missed me and hugged me. It felt very human and caring and I interpreted this as a demonstration of acceptance into their community. I became close to different people at different times, this caused internal conflict at various points though, for example; I discovered one of the volunteers was paying a lot of money in taxis to volunteer at the Day Hospital, she also disclosed to me that she was finding it financially difficult. As I learnt more about this woman who was widowed and felt lonely, I began to feel sorry for her and almost guilty that she spent so much money coming to volunteer. I found myself sitting and chatting with her for long periods at times and wanted to offer her a lift but felt that this may place me in a difficult situation or ostracize me from access to some of the other volunteers. As I discussed in Chapter 3 when studying a social world, I as the researcher, inevitably became emotionally involved with the place and people of the Day Hospital. This was something I eventually came to embrace as I acknowledged emotions are enacted in all occurrences in life and influence how we understand our world. I was not a disembodied observer, nor should I have been, but enacted my role within the Day Hospital as an emotionally present human. To manage these feelings and emotions, I continued to document my reflections and utilised my academic/clinical supervision to its full extent.

4.6 Establishing trustworthiness: credibility, dependability and transferability.

Establishing trustworthiness is an important element of any qualitative study (Rettke et al. 2018, Ryan and Bernard 2000), as researchers it is important to demonstrate quality and rigor in the findings we present. In this section I will briefly discuss the concept of trustworthiness within qualitative research, I further highlight the steps I undertook to ensure coherence between the aim of the study, methodology and methods used in order to demonstrate credibility, dependability and transferability of the findings presented.

The value and trustworthiness of qualitative research depends, to a large extent, on the rigour with which data was collected, interpreted and reported (Cypress 2017, Mays and Pope 1995). The basic premise of trustworthiness in qualitative research surrounds the question of; how do I, as the researcher, convince both you reading this, and myself, that the findings of the study are worth taking account of? (Denzin and Lincoln 2011). In quantitative research the concept of rigour is used by researchers as an expression of objectivity and measurement, however in qualitative research, rigour can be interpreted as thoroughness (Holloway and Galvin 2017). The undesirable human biases and perspectives that can confound results in quantitative research, are considered inevitable and essential in qualitative research (Holloway and Biley 2011, Leung 2015). However, it is important that in accepting this inevitability we also transparently demonstrate how these human perspectives were considered and affected the study.

Due to the diversity of methodologies and philosophical stances in qualitative research, there is no consensus for assessing quality in such work (Leung 2015). Several approaches have been proposed focusing on rigor within the methodology, or in the interpretation of the findings (Barbour 2001, Lincoln et al. 2011), although each may have its merits within a particular methodological or interpretative study, ultimately all such assessments look for cohesion between the aims of the study and methodology chosen, and justification of the processes made throughout.

There are many terms used throughout the literature to discuss quality. Validity, reliability and generalisability are commonly accepted terms throughout quantitative research, though these do not easily translate to qualitative studies. For example; in quantitative studies reliability refers to the replicability of a study i.e. that the results of a study can be replicated under similar conditions. In qualitative research however the researcher becomes the research instrument and therefore qualitative research cannot be replicable in the same way as a scientific study. Nevertheless, qualitative research can reflect the experience and activities of research participants, through transparency of methods, positionality of the researcher and contextual writing, qualitative research can produce dependable findings, which reflect the data they collect and analyse (Guba and Lincoln 2005). By documenting transparent decision making and processes, dependability can be used to describe the research rather than reliability (Guba 1981). Similarly, generalisability refers to the application of study findings to other settings and populations, however most qualitative studies look to examine a specific case or phenomenon, and therefore generalisability of such findings is not possible (Holloway and Galvin 2017, Leung 2015).

Throughout this thesis my intention is to establish trustworthiness and coherence in my claims by not only providing rationale for decisions made, but also reflecting upon these decisions from my epistemological viewpoint. I employed several strategies to achieve and demonstrate credibility, dependability and transferability which I will now describe.

4.6.1 Credibility

Credibility is concerned with the confidence in how the conduct and analysis of the study is conducted, coherence between methodological and epistemological values and how plausible the representation of the research findings are (Moser and Korstjens 2018, Lincoln and Guba 1985). In the previous chapters I outlined and justified my methodological choices and processes to carry out the research. In doing so I aimed to demonstrate cohesion between the aims of the study, the methodology and my epistemological values. This meant evaluating the fit between the various elements of the study and the research question (Rashid et al. 2015). By transparently expressing these workings I aim to demonstrate credibility to the choices I made at each stage of the study (Polit and Beck 2012, Silverman 2004).

Credibility of this study was also maximised through prolonged engagement, over several months in the field. Prolonged engagement enabled me to gain a deeper understanding of the culture of the Day Hospital, I was able to observe both sporadic and ritualistic events which deepened my understanding of the culture. Denzin and Lincoln (2011) highlight how prolonged involvement helps to build trust and enables the relationship between the research and those within the field to deepen. My involvement within the field also included early engagement with social actors during the planning stages. Through weekly visits and involvement within the development of the study I was able to begin to build rapport and relationships that enabled me to identify potential issues, such as the differentiation of the patient and relative focus groups as described in chapter 4.3.1. In total my involvement in the field lasted just under two years, this length of involvement enabled me to develop a rich and detailed understandings about the cultural practices within the Day Hospital and those within the field. This was further substantiated by observing hundreds of different patients and relatives access the services, which contributed to the credibility of the data collected (Hammersley and Atkinson 2019).

Persistent observation and concurrent ongoing analysis of the data within the field added further credibility to the findings (Moser and Korstjens 2018), as ideas and themes emerged I read and reread the data, considering links and repeated until it was felt that no new themes were evident (Guba and Lincoln 2005).

4.6.2 Dependability

Dependability in qualitative research refers to the robustness of the research processes. In quantitative research the concept of reliability is used to highlight replicability of procedures and study findings (Cypress 2017). The nature of social phenomena however means that replicability cannot be achieved (Pandey and Patnaik 2014), instead we look to show that the journey to our findings was thorough and robust and therefore dependable. One of the ways in which I aimed to establish dependability in my findings was through explicitly describing how data were collected, analysed and interpreted and how and why decisions were made at different stages (Denzin and Lincoln 2011, Moser and Korstjens 2018), detailing the context within which the data were collected, analysed and interpreted. Context in this sense is not only description of the environment and how the study came to be, but also my personal characteristics, background and thought processes which will have shaped and have been shaped by my experiences within the field (Robson 2004). The self is always present in fieldwork, as a nurse and carer myself I felt that I understood some of the feelings, thoughts and experiences within the field, yet my relationship with the participants needed critical analysis (Holloway and Biley 2011). By keeping a reflective journal (see chapter 6), where I could document my thoughts, feelings and judgements, I was also able to self-scrutinize and therefore understand the context within which my observations and interpretations occurred. Consideration and documentation of these reflexive processes adds trustworthiness to the findings by providing the context within which they happened.

Understandings generated from the prolonged engagement in the field during phase 1, were also deepened, expanded and validated by the triangulation of data from phase 2. Ideas generated from phase 1 analysis laid the foundations for the topics for the focus groups enhancing the trustworthiness of the data (Shenton 2004). The data were considered not only by myself but also by my supervisors. We brought our thoughts and interpretations together at regular intervals to discuss and compare, if there were differences in concepts, this was discussed until themes were felt to best represent the data. Preliminary findings were also presented at academic conferences (Cox 2017, Cox 2018, Cox 2019) where ideas were discussed further strengthening the iterative data analysis (Jones and Smith 2017). By using multiple approaches of data gathering (participant observation and focus groups) and cross analysis, data triangulation was established which added richness and depth to the findings (Moser and Korstjens 2018).

4.6.3 Transferability

Transferability concerns the applicableness of findings to other settings or populations (Moser and Korstjens 2018). Generalisability is an important concept in healthcare research, if not a contentious one within qualitative studies. In healthcare research funding bodies may not be receptive to ethnography due to its lack of generalisability (Savage 2000). Although it would not be possible to generalise the findings of this study to other populations or institutions, the thick description I have presented offers new insights and understandings of the processes of identity construction and frailty. By producing the story of this ethnography through thick description of the processes and events within the field and therefore note the context within which the data was constructed, I aim for the reader to gain sufficient detail to assess whether the findings are transferable to other settings (Moser and Korstjens 2018).

Chapter 5 Methods Phase 1: Entering the field with an open book and open mind.

In the previous chapter I described some of my experiences whilst setting up and carrying out my data collection. In this section I will describe in more detail the data collection techniques used in phase 1 of the study and how this data was analysed. The aim of phase 1 was to explore and understand the structure, interactions and discourse of all those who work as part of the Day Hospital team, including the volunteers, and those who attend the Day Hospital as a patients, relatives or carers. 100 hours of observations and participant observations were conducted over a nine-month period to gain a sense of the day-to-day functioning of the Day Hospital and understand discourse and interactions particularly in relation to frailty and identity.

Participating in ethnographic research combines two distinct activities;

- First entering the field, the unknown world, participating in daily routines, developing relationships and making observations on these activities and interactions.
- Secondly, the production of accumulative written accounts of these observations and reconstruction of that world (Emerson et al. 2011).

In this study I used three main methods of data collection, observation and participant observation in phase 1 and focus groups in phase 2. In this next section I will detail the techniques used to collect the data in phase 1.

5.1 Study participants – Phase 1

During phase 1 all staff, volunteers, patients and relatives or carers who attended the Day Hospital were classed as participants unless they actively opted out of the study. Many patients are accompanied to the Day Hospital by a relative and/or carer. In most cases this was a spouse and occasionally an adult child or close friend. For older people with frailty their spouse or partner often becomes an informal carer, supporting their loved one both functionally and emotionally. I felt it important to include this population in the study as they are likely to be playing an integral role in the construction of the patients' sense of self-identity, as well as their own. Many of the relatives were in their 70s and 80s, even the children of the patients were often approaching older age themselves, and this meant that in addition to their caring roles, some were experiencing their own ill health. All relatives and/carers were informed of the study if they attended with a patient, they were given the same information and opportunity to opt out of the observational phase. During phase 2, relatives were not approached unless the patient that they came with agreed for them to be approached and invited to participate, which I describe in more detail in the next chapter. Day Hospital staff were classed as any members of staff, full or part time who are based within the Day Hospital. I did not include auxiliary services that may very occasionally remote into the Day Hospital from other parts of the hospital such as, housekeeping, post workers or x-ray staff. Table 5 lists the included roles.

The Day Hospital also has a dedicated number of volunteers, many of who have worked there for over 10 years. The volunteers provide services to the unit daily, these include the preparation and serving of drinks and food for patients and their relatives whilst attending, cleaning the waiting and kitchen areas and organising and maintaining the bric-a-brac table and seasonal raffle tables. All volunteers who worked in the Day Hospital were included in phase 1 as participants unless they chose to opt out, which none did. All of the volunteers were over the age of 65 years apart from one who was in their late 50s.

Table 5: List of included roles for participation in phase 1

Clinical/Non-Clinical Management	Day Hospital Manager	Services Manager	Clinical Manager		
Medical Doctors	GP trainee rotations	Trust registrar	Consultant Physicians and Gerontologists	Junior Doctors	Medical students
Nurses and nursing auxiliary staff	Advanced nurse Practitioners	Nurse Practitioners	Staff Nurses	Healthcare assistants (nursing)	Nursing Students
Therapy staff and therapy assistants	Senior Physiotherapists	Senior Occupational Therapists	Rotational Physio therapists	Rotational OTs	Student therapists
Administrative staff and other non-clinical staff	Receptionist	Administrator	Transport drivers		

5.2 ‘Opt-out’ consent – Phase 1

‘Opt-out’ consent is when participants are included in a study without actively volunteering to take part, their consent is presumed and only excluded if they actively ‘opt-out’ (Nordfalk and Hoeyer 2020). ‘Opt-out’ consent however can be contentious for two main reasons, firstly some suggest that it undermines the concept of freely given consent or a violation to a person’s autonomy (Prabhu 2019). Secondly people may find it difficult to ‘opt-out’ due to power imbalances and fear that it might affect their treatment or their job (McDermid et al. 2014). Nonetheless I strongly felt that my observations and other interactions would be more truthfully represented if an ‘opt-out’ system was used, additionally in the planning stages representatives from all participant groups had deemed this method as ethically acceptable (Hammersley 2019). Next, I describe how members of these groups were informed of the study and given opportunity not to participate.

5.2.1 Informing patients and relatives in Phase 1

Participants were notified of phase 1 of the study via several A3 sized Study Posters (Appendix 5) in the public areas of the Day Hospital that were used by patients, relatives, volunteers and staff. The posters had an overview of the study and were designed to provide information about the study topic, that observations would be carried out and what the data may be used for, without overloading the reader with too much detail. The poster had my contact details if further information was required or if they did not want to take part. The poster was designed with the patients and relatives readability in mind and therefore had large black text on a yellow background (Rello and Bigham 2017). A brief sentence stating that the Day Hospital was participating in an observational study was also added to the initial appointment letter for every patient and at each initial assessment the patient was informed that the study was running and given an A5 version of the study poster to take away with them and informed about the opt-out system. Consent was assumed unless a person opted out of the study by contacting me either directly or through a member of staff. I had two patients contact me directly and ask for further information regarding the study, but no one opted out of this first phase.

5.2.2 Informing staff and volunteers in Phase 1

All staff and volunteers were explicitly told that their inclusion in the study was voluntary at the team meetings. Although the staff appeared enthusiastic, I was aware of the inherent power divide between them and the management team and felt it important that they understood that I would not inform anyone if they choose to ‘opt-out’ and that their participation or non-participation would not affect their job. All new or rotational staff were also given this information and offered the same opportunity to opt-out of the study. This process was approved by the South-Central Berkshire NHS ethics committee as detailed in section 4.4.2.

Once all approvals were in place the therapy and nursing teams began to inform patients and relatives that the study was in progress, I didn’t enter the field for approximately two weeks so that I felt confident that all those attending the Day Hospital would have been informed of the study. Once the observation period started, I did periodically, seek to obtain verbal consent to observe, this generally happened during individual or group interactions i.e. individual patient’s treatment sessions or assessments, patient teaching sessions or group exercise sessions. I did this as it felt a natural humanistic approach to my presence and my interactions with people. My presence in the field was overt in the sense that I wasn’t hidden away from view, nonetheless the level of overtness was adapted depending on the event, interaction and person. Plankey-Videla (2012) talks about this in terms of being a reflexive practitioner, as I progressed through the data collection period, I came to learn that consent itself was fluid and needed to feel appropriate and proportionate to the situation. For example, it felt morally unsound and unnatural not to explain my presence in a small room with a patient and staff member, and I came to realise that legislative ethical approvals did not mitigate moral solutions to issues in the field or remove my moral autonomy.

5.3 Data collection phase 1: Observation and participant observation

Participant observation is almost universally accepted as a central feature of ethnography (LeCompte and Schensul 2010; DeWalt and DeWalt 2011; Sandiford 2015; Fetterman 2019), and the most common method used by ethnographers carrying out fieldwork (Hammersley and Atkinson 2019; Kirner and Mills 2019). It is, as its name suggests, the participation with and observation of people, their environments and practices (Laurier 2016; Fetterman 2019). This contrasts with observation, where the researcher passively observes remotely without participation with the group activities (Jones and Smith 2017). The process of participant observation was enabling, as it allowed me to experience and learn about the activities, rituals and colloquialisms of the Day Hospital and those within it (Kawulich 2005). Using participant observation, I was also able to witness nonverbal responses, interactions and communication across various activities, which facilitated a deeper understanding of the culture (Fetterman 2019). Working and participating with those within the Day Hospital further supported the understanding of how things were organised and prioritised and how individuals related to each other, over time this demonstrated and confirmed patterns of organisation, behaviour and rituals which could not have easily been seen in other ways (Schensul and LeCompte 2013; Spradley 2016).

I understood participant observation to mean not only observing the interactions and activities that participants carried out but trying to understand how others experience their worlds through participating in these activities. Initially this involved me entering the physical landscape of the Day Hospital and grounding myself in that environment. I took note of the environment, the décor, colours and spaces, I drew diagrams and floor plans to understand the layout and the potential paths people may take. Figure 5 shows an example of an early floor plan and footfall pathways that I documented.

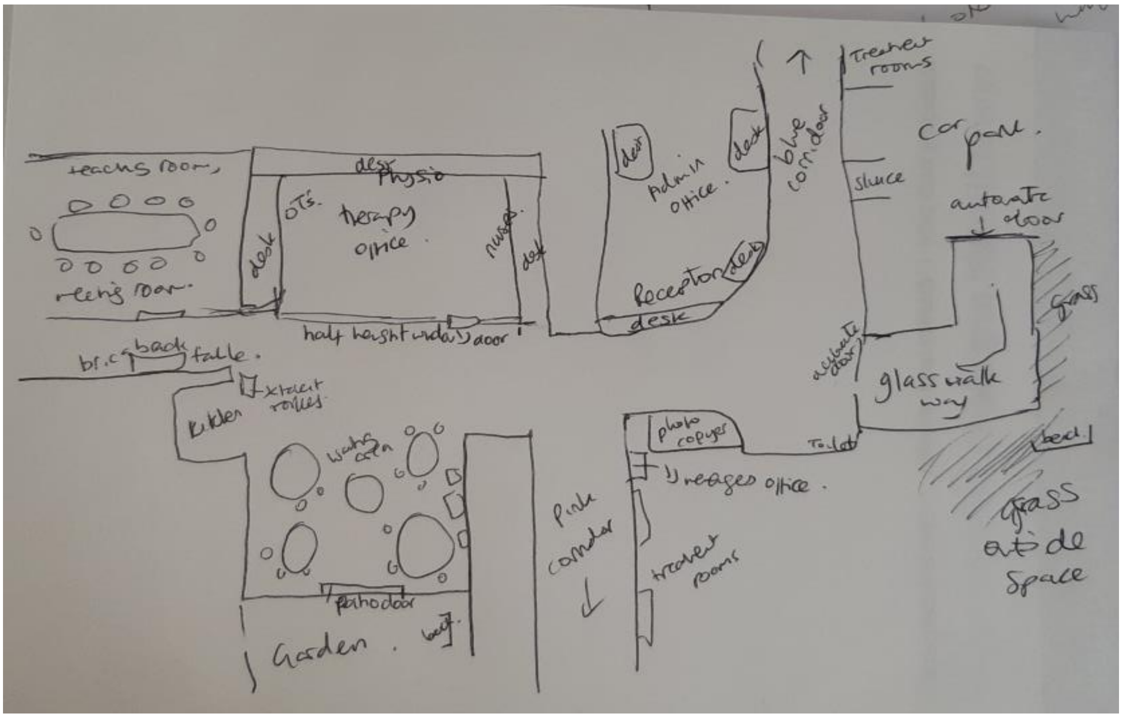


Figure 5 Example of sketched floor plans of Day Hospital

At the outset, as unassuming as the process may sound from its name, the reality of participant observation was quite overwhelming. In the early days of the study I found myself spending several hours observing from afar in The Day Hospital trying to understand and get a sense of my surroundings. I remember feeling concerned, panicked even that I didn't feel like I was 'collecting data', however as time passed and I began to consider and analyse my fieldnotes I realised that this passive observation and immersion in the environment at an early stage enabled me to get a feel for the organisational structure, how events and routines occurred and the order in which they happened. This initial process enabled me to feel better equipped to understand these events when I took a more participatory role (Emerson et al. 2011; Fetterman 2019). Once I did start to actively participate in activities and processes, participant observations enabled me to explore the enacted experiences of those within the Day Hospital. Before the data collection began, I had a loose framework of areas I may like to observe, however this evolved sometimes daily. I attended different days, different group sessions and individual assessments in order to get a broad scope of activity. Participating actively within the Day Hospital community I constantly assessed my role, my relationships and positionality and used these experiences to move and develop my research focus as the study progressed (Fetterman 2019).

At the beginning of each day I tried to enter the field with an open mind and literally an open book. I entered with the concept that I knew nothing, and even what I thought I knew could be different. I wrote down as much as I could, even if it was something I had already witnessed and documented. In addition to the context that these interactions occurred, i.e. the place, time and actors, I also paid attention to the behaviour, language (verbal and non-verbal) and actions of individuals. After a few months of generally observing, participating and analysing the data, I became more selective in my observations. With increased exposure in the field I was able to participate in observations that felt more relevant to both the initial research question and the evolving ones (Hammersley and Atkinson 2019). Over time I became more attuned to certain words, conversations or actions which appeared to make sense of immerging themes. As I became immersed in the Day Hospital culture I began to follow intuitions or 'hunches' about what to participate in and observe, the hunches acted as hypotheses (LeCompte and Schensul 1999) and helped me to work out how things worked and why they happened as they did. The data were continually edited and managed in the field as interactions and roles progressed and were displayed, noting my thoughts and initial ideas surrounding a situation. I aimed to spend the equivalent of two days per week in the field, sometimes I spread that over a number of days and I changed the days each week to try and ensure that I captured the full range of activities that occurred over the time frame. If an event or meeting was advertised then I would attend this specifically, in addition I participated in any social events at the Day Hospital such as the annual Tea Dance or bring and share lunches. All my observations were recorded through written fieldnotes.

5.3.1 Fieldnotes: structuring the unknown.

I had an intense awareness that it would be important for me to structure what I was planning to observe, how I would carry these observations out and how I would document them (Emerson et al. 2011; McGarry and Mannik 2017). The difficulty as DeWalt and DeWalt (2011) point out, is that when entering an unknown world, it is hard to fully anticipate what may or may not happen and therefore what you may want to observe. Most ethnographic observations are documented through written fieldnotes (Emerson et al. 2011; Fetterman 2019), but one of the greatest challenges for myself, and ethnographers in general, was the representation and transformation of my observations into fieldnotes (Schensul et al. 1999). In conjunction with participant observation, written fieldnotes are at the core of ethnographic research (Emerson et al. 2011). It was important for me to create records that could be considered accurate so that the data was not only usable, but could be validated and interpreted through additional observations, interrogation and sharing with others (Schensul and LeCompte 2013).

The observations and fieldnotes were my interpretations of the social world that I was participating in. I was the actor in the interaction, and I was required to define the situations I encountered. To do this I needed to understand the process and sequences of the interactions that played out. The quality of my fieldnotes would ultimately determine the integrity of their representation and ease of their interpretation and analysis. I searched many texts to try and comprehend what I should be writing in my fieldnotes, but as O'Reilly (2009) highlights, there are few methodology texts that tell people what to record. I found a paucity of visual examples of field notes and as time progressed realised through my own field notes that this may in part be linked to the difficulty in anonymising and deciphering these initial jottings. Figure 5 is an example of an early field note.

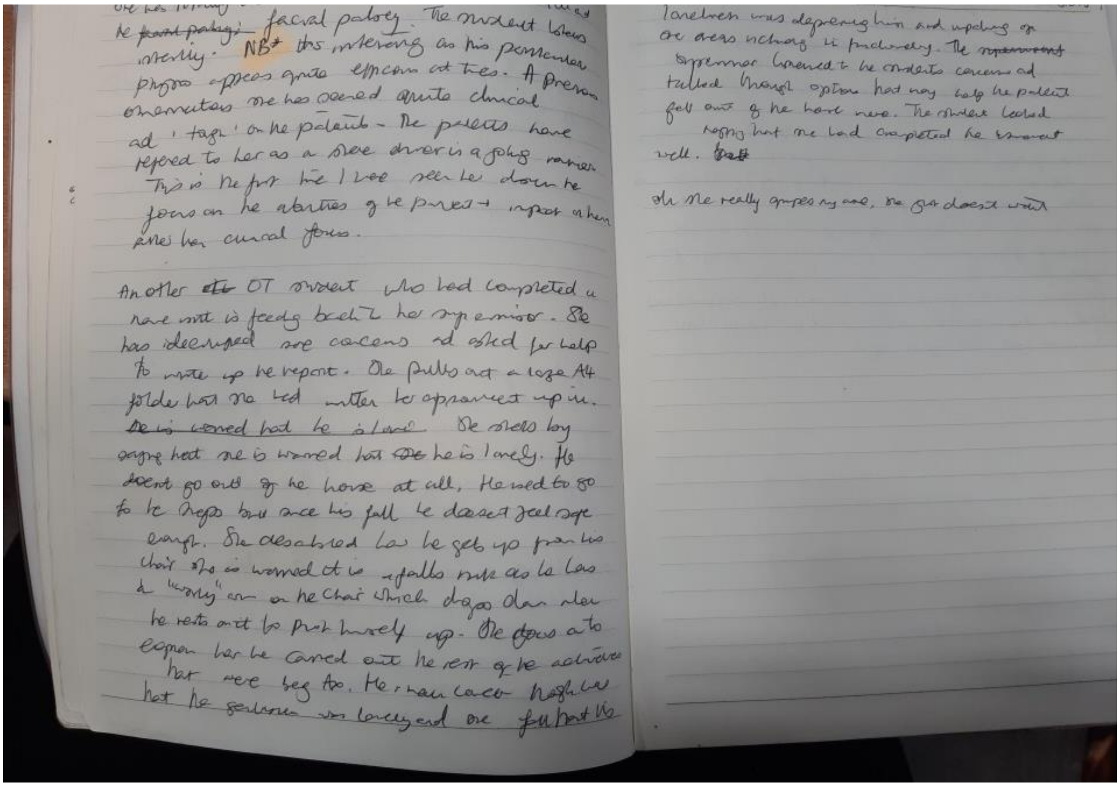


Figure 6 Field note example

At the start of my observations I would often feel panicked to document everything ‘accurately’ but quickly discovered that accuracy was not really the aim. I strove to remember and record observations truthfully but as the study progressed, I learnt that there was no accurate ‘truth’ for me to document, it was my representation of what I observed. I took comfort in Atkinson’s (2015) suggestion that the author of fieldnotes should recognise that they are that - an author, an ethnographic author is different to a stenographer as they are not simply recalling and transcribing from memory, rather they go beyond this to evoke the writings of cultural constructions.

Even accepting that I could not replicate an accurate truth, I still faced practical challenges in the field of balancing my presence and participation with documenting my experiences. In ethnography, observing and writing should not be seen as separate actions but rather as interdependent activities that are at the core of ethnographic methods (Emerson et al. 2011). The issue I found was that I did not want to document observations in areas where people could see me as I felt this could potentially jeopardise the relationships I was attempting to build and highlight my ‘outsider’ status as highlighted in chapter 3. I would try and find an empty room or go to a different area of the hospital after an observation period. The challenge with this was that observations were continuous, I may have 20 or 30 interactions with people throughout an observation period, by the end of which recalling the initial exchanges could become woolly. I did consider audio recording the interactions and observations, but the Day Hospital space is large, and it didn’t seem effective or feasible to use audio recording for such a large observational area, in addition there would have been ethical implications linked to this type of data recording.

Ethnographers ultimately produce a written account of what they have experienced yet all have different ways of doing so (Kinchin and Francis 2017; Fetterman 2019; Kirner and Mills 2019). I continued to search for a more effective way to record the data, eventually settling on a two part process suggested by Schensul and LeCompte (2013).

Step 1: I used a small book to document key words, phrases and shorthand observations in the field, I call these inscriptions. These included the area I was in, who was there and a prompt for the observation I was participating in for example, “*patient with stick talks about garden*”. If I engaged in an informal conversation with someone which felt significant, I would endeavour to document the summary conversation immediately after it; over time I found that my memory for interactions improved and I was often confidently able to recall direct quotes from conversations. If I deemed it appropriate, I may also ask the person if it was ok to document what they were saying there and then. This did happen on a few occasions but mainly when the content felt highly significant to the emergent themes and I didn’t feel my notations would negatively impact on the interaction happening. At the end of an observational period I would move on to step 2.

Step 2: After an observational period, I would dedicate an allotted time, often a few hours, to expanding my initial inscriptions in my notebook to larger fieldnote accounts. These accounts were developed and re-developed over time. I would read and re-read these fieldnotes, with the aim of evoking additional memories about the event or interaction in question. As the weeks progressed, I found my writing became more sensorily descriptive, drawing out more tangible feelings, senses, emotions and narratives for the reader. Alongside these descriptions I would add reflections and further questions to consider and investigate.

As the months passed the fieldnotes accumulated into a larger corpus of data. They were produced observation by observation, day by day over time without initially knowing which observations would be useful. Because of this I had to consider the data as a loose collection of material that may or may not be incorporated into an ethnographic narrative (Emerson et al. 2001). As my corpus of fieldnotes grew I started to develop a more systematic, computerised system, typing up and further expanding my fieldnotes into narratives using the fieldnote template shown in Figure 6.

At various points I would go back to my written fieldnotes and transcribe them to the computerised template adding memos, diagrams and reflections. I added the date and time frame whilst I was in the field in case this became relevant to any observable patterns throughout the analysis. I describe the analysis in more detail in section 5.4, but a key point to note was that analysis started, and ran alongside the data collection in the field, it was not a separate process to data collection but an integral part of it (Fetterman 2019; Kirner and Mills 2019). This process of analysis, which I describe in the next section, identified themes which were then used to frame and lead the structure and content of the focus groups in phase 2.

Phase 1 – Participant observation	
Date:	Time period:
Researcher: Chantel Cox	Location:
Descriptive comments/ Observer reflections What was happening generally? How did it make me feel? What did I sense? Relationships with other interactions and observations seen before. Why did I choose that area/time frame? Why did I notice what I noticed?	

Figure 7: Fieldnote template

5.4 Analysing ethnographic data

Similar to instructions on data collection in ethnography, the process of analysing ethnographic data is often missing from the literature (Gobo 2008; Jones and Watt 2010). Debate exists surrounding how systemised the process of analysis of ethnographic data can be, and some ethnographers argue that the application of systems to the data goes against the theoretical perspectives behind ethnography (Brewer 2000; Hammersley and Atkinson 2019). Consequently, there is no one universally accepted system for analysing ethnographic data and often analytical processes are adapted and created dependent on the needs of a specific project (Angrosino 2007).

Ethnographic data are subjective and can be complex to collate, manage and analyse, in ethnography the process of analysis starts within the field and continues throughout data collection and beyond (Angrosino 2007; Fetterman 2019; Kirner and Mills 2019). Congruous across all ethnographic analysis techniques is the search for relationships, interaction and patterns that emerge in different contexts, with the researcher looking to identify similarities and differences between them (Fetterman 2019). My undertaking was not only to try and recreate and convey the depth of my experiences in the field to the reader but develop those experiences into a meaningful narrative which identifies the commonalities and differences that construct sense of self-identity in the world of the Day Hospital. The cultural depth and reminiscent nature of fieldnotes enabled me to iteratively cultivate and expand that data through the analytical process. There are a variety of techniques that ethnographers use to create evocative narratives from fieldnotes, many of which involve an element of storytelling (Emerson et al. 2011; Fetterman 2019).

I must be honest, prior to my fieldwork the thought of analysing my data somewhat filled me with dread, I spent several months trying to grasp what this would look like for me. Coming from clinical practice, which was often highly systemised, I searched for a concrete way to achieve this analysis and struggled with the lack of clarity on when and how to undertake it. Through reading I understood that analysis was, in its simplest form, the exploration and questioning of my observations and subsequent interpretations and synthesis. Although inductive these questions and interpretations did not materialise purely through the empirical observations and field engagement but were also derived, in part, from my prior clinical knowledge and experience and published work on the topic (Atkinson 2015). I came to recognise that my growing pile of observations, written fieldnotes on my desk were not awaiting analysis, I had already started the process of analysis though my annotations, questioning and reflections. Angrosino (2007) describes two main stages of data analysis:

> *“**Descriptive analysis** is the process of taking the stream of data and breaking it down into its component parts; in other words, what patterns, regularities, or themes emerge from the data.*
>
> ***Theoretical analysis** is the process of figuring out how those component parts fit together; in other words, how can we explain the existence of patterns in the data, or how do we account for the perceived regularities”*
>
> *(Angrosino 2007, pg 67).*

I now go on to describe these stages in more detail for phase 1 of the study and the steps involved in each, bearing in mind that each step did not always occur sequentially, but often either repeatedly or simultaneous to the data collection.

5.4.1 Phase 1 Analysis: In field descriptive analysis

5.4.1.1 Step 1: inscription and description.

Inscription in this context is the art of making physical and mental notes, it is the initial thoughts and senses, as well as questions I asked myself as events were enacted, things I needed to investigate further, the ‘hunches’ I experienced. LeCompte and Schensul (1999) suggest that everyone tends to think first and write later, and our thinking is guided by things that are culturally accepted as worthy of notice whether that be people, places or behaviours in our environment. As I previously described, I had to consciously go beyond my own personal ethnocentrisms in order to recognise and document things that appeared noteworthy not only to myself but to those I was observing. I was attempting to capture social construction as it was occurring therefore I needed to be mindful that as an ‘outsider’ things that appeared meaningful to me, may not be to those in that social world and vice versa (Emerson et al. 2001; Angrosino 2007).

Although I opened my mind to these alternate options of meaningfulness, I could only document them, as the data collection instrument, through my own perceptions, interpretations and understandings of the world, and based upon my research enquiries. Initially re-reading these inscriptions and expanding their meanings appeared rudimentary, yet this process triggered my memory for people in interactions and descriptions of places, as months passed these inscriptions became more evocative than simply prompt words on a page, they would evoke memories or emotions and atmospheres, smells and sounds. Atkinson (1992) describes these evocative understandings as almost Proustian experiences of remembrance.

Once these initial thoughts and observations were inscribed they then required development, LeCompte and Schensul (2010) term this step ‘description’. The descriptive step looks to expand initial inscriptions into narrative representations of events; this consisted of developing my fieldnotes from my initial jotted notes into a more robust and resonant descriptive narrative. This process was very iterative and fluid, as previously mentioned I would spend time at the end of an observation or day writing my fieldnotes, alongside these descriptions I would annotate additional reflections and further questions and ‘hunches’ that I wanted to investigate. These comments, annotations and hunches formed the preliminary analysis, contextualising and rationalising events and interactions, whilst highlighting potential patterns and relationships. I quickly learnt not to become precious about these initial thoughts and went back several times to further expand an idea or point or change my initial thought when new findings came along. The fieldnotes that I created would never be a perfect reconstruction of all that happened; they were developed and created not only through my observational lens but also expanded and guided through my analytical perspective (Atkinson 2015).

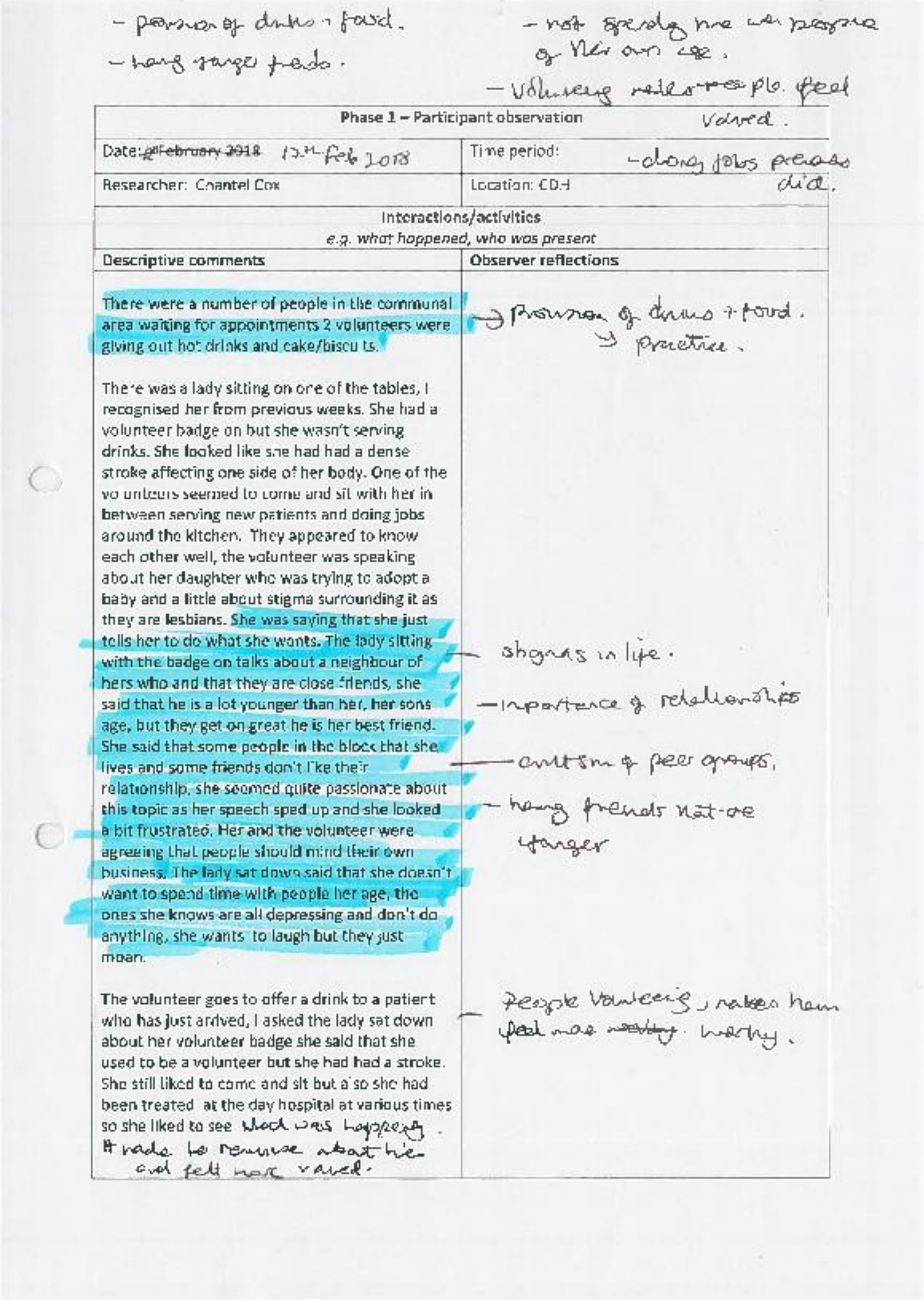
5.4.1.2 Step 2: Theoretical analysis - Recognising patterns and regularities

Towards the end of the initial phase of observations I returned to the corpus of field notes and read them in their entirety, Emerson et al (2011) notes that many researchers find that writing fieldnotes gives way to reading them, yet this is a crucially important analytical step. The process of returning and rereading the fieldnotes enabled me to further elaborate and cultivate those insights and hunches which I had documented in the earlier weeks and months. Returning to these early notes, I opened my mind to re-immerse myself in the setting; I expanded these descriptions until I felt that they would be comprehensible and relatable to a reader who was unfamiliar with the environment. As the observations progressed, reading and re-reading the fieldnotes became more significant as patterns and linkages became apparent. Being able to recognise and compare these patterns across the corpus of data meant that I could also follow more focused observations.

Recognising patterns and linking occurrences and commonalities contemporaneously to the observations meant that I was producing definitions of these patterns or *codes* in the field. By code I simply mean attributing a label to a section of data which may summarise and give meaning to that data. These initial codes were very loose and sometimes quite obscure, I felt wary of defining something too early in the research but made a point of adding these initial codes as they were often my embodied reaction to something at the time or when recalling the event. As can be seen in figure 7, these initial codes might apply to a particular observation in full or in part, also numerous codes can be applied to the same observation, for example I attributed the codes to the fieldnote in figure 7:

- Stigmas in life
- Importance of relationships
- Criticism of peer groups
- Having younger friend

At this stage some of the supervisor team also reviewed the anonymised fieldnotes, deriving their own codes. We met weekly to discuss and review these, this enabled me to incorporate alternative perspectives that I had not considered into the analysis.



- provision of drinks + food.
- having younger friends.

- not spending time with people of her own age.
- volunteering makes people feel valued.
- doing jobs people did.

Phase 1 – Participant observation	
Date: ~~8th February 2018~~ 13th Feb 2018	Time period:
Researcher: Chantel Cox	Location: CDH
Interactions/activities *e.g. what happened, who was present*	
Descriptive comments	**Observer reflections**
There were a number of people in the communal area waiting for appointments 2 volunteers were giving out hot drinks and cake/biscuits.	→ Provision of drinks + food. → practice.
There was a lady sitting on one of the tables, I recognised her from previous weeks. She had a volunteer badge on but she wasn't serving drinks. She looked like she had had a dense stroke affecting one side of her body. One of the volunteers seemed to come and sit with her in between serving new patients and doing jobs around the kitchen. They appeared to know each other well, the volunteer was speaking about her daughter who was trying to adopt a baby and a little about stigma surrounding it as they are lesbians. She was saying that she just tells her to do what she wants. The lady sitting with the badge on talks about a neighbour of hers who and that they are close friends, she said that he is a lot younger than her, her sons age, but they get on great he is her best friend. She said that some people in the block that she lives and some friends don't like their relationship, she seemed quite passionate about this topic as her speech sped up and she looked a bit frustrated. Her and the volunteer were agreeing that people should mind their own business. The lady sat down said that she doesn't want to spend time with people her age, the ones she knows are all depressing and don't do anything, she wants to laugh but they just moan.	– stigmas in life. – importance of relationships – criticism of peer groups, – having friends that are younger
The volunteer goes to offer a drink to a patient who has just arrived, I asked the lady sat down about her volunteer badge she said that she used to be a volunteer but she had had a stroke. She still liked to come and sit but also she had been treated at the day hospital at various times so she liked to see what was happening. It made her reminisce about her and felt more valued.	– People volunteering, makes them feel more ~~[illegible]~~. worthy.

Figure 8: Example of field notes with initial codes

Once data collection was complete in this phase, I compiled a list of initial codes with respective fieldnote dates. To the right of the list I began to make linkages across the codes as patterns and relatedness became more apparent as in Figure 8.

2nd Nov		
mediatory roles		Link to bring and share.
lunches, eating together		Managing expectations
"It's not about identifying issues it's about identifying solutions".		Individualised care
10th Nov		
Laughter		link to colours and impact on feelings
Togetherness		
Shared joy (shared experiences)		
Bric a brac table		
Colours		
Brightness		
layout		
14th Nov		
Loss		fear and losses
loneliness		
Bereavement		
Fear		
More fearful when alone		
gender/generational differences		
Women therapists		
Pride		
Pressure to move on after loss		
21st Nov		
Peer praise		
Rituals		
Positive praise for achievement		
Minimising disappointment		
Feeling of role within a group		
Hierarchy		
Listening and valuing patient experience		
30th Nov		
Anticipation waiting for treatment		Fear of losing independence
Being recognise		Distancing yourself from peers – Warmoth
Lack of engagement = deterioration		Refreshments

Figure 9: Initial coding chart

In my original plan for analysis I had included the use of NVivo coding software, a qualitative data analysis computer software package that aims to manage fieldnotes and create conceptual maps of what is happening within the data

(Bazeley and Richards 2000). I had planned to use this as I felt it would afford me some tangibility to the sea of data that looked potentially overwhelming. I went on the software training courses and in theory, the concept of a systematic categorisation of data gave me a sense of security, a metaphorical safety net. In practice however, I soon realised that the use of software made me feel disconnected from the data. As my methodological understanding of ethnography deepened, the use of this software made me feel increasing detached from the data and that the concepts generated did not feel conducive to fully representing my experiences in the field. I had spent months immersing myself in this world, being present in the moment to understand others' experiences, yet at this crucial stage I felt wholly disembodied from it. I decided that the supervisory support and manual techniques of analysis would be more beneficial to me, and truthful to the data as I developed themes.

5.4.2 Phase 1 Analysis: After the field – thematising the data

On a personal level there was something about the physicality of touching the written fieldnotes, annotating and re annotating, reading, interpreting and reinterpreting them in their original form that I felt I needed in order to convey a candid picture. I printed all the initial codes and laid them out on a large sheet of paper, moving them around until I found other codes that felt related and began to form groups. I did not set any analytical parameters at this point in terms of what constituted a group other than they had a sense of relatedness to each other. This is less mystical than it sounds, by this point with my research question fully embodied and influenced my perceptions and I had started to become sensitised to specific areas of interest through immersion of the data over the span of the study. As Atkinson (1992) highlights this analytic work was a highly engaging, and for me a physically tactile process.

I worked alongside my supervisors working and reworking these initial codes into groupings of similar sense making. This process took several weeks, groupings were not inert once identified and were open to regrouping through further discussion. This process was followed by the development of a visual conceptual map to explore and show the relationships between groupings. The initial conceptual map was very large and complicated, again I returned to the use of pen and paper, laid out on the floor or large table in order to get oversight of the data and patterns that may form.

Figure 10: Visual conceptual map of data phase 1

I firstly used sticky notes, so fluidity of movement was possible and different colours to create linkages for example; pink for cross theme connections and blue for grouping initial themes. Several conceptual maps were constructed in conjunction with the supervisory team (see Figure 10, 10 and 11 as examples). With each developing version of the conceptual map stratums of initial codes began to layer, amass and form until a more robust and structured group could be identified.

These larger groups, by nature, became more abstract from my initial fieldnotes, having been so immersed in the data by this stage I started to feel lost in the findings. To help with this I went back to my overarching research question for this phase, trying to understand the discursive and behavioural processes which contribute to the identities of older people with frailty in the Day Hospital. I started a new map with this question at the centre and placed groups around it, these groups were positioned with relatedness to each other, for example: ***fear of loss of independence*** was placed close to ***issues that felt uncontrollable by the patient.***

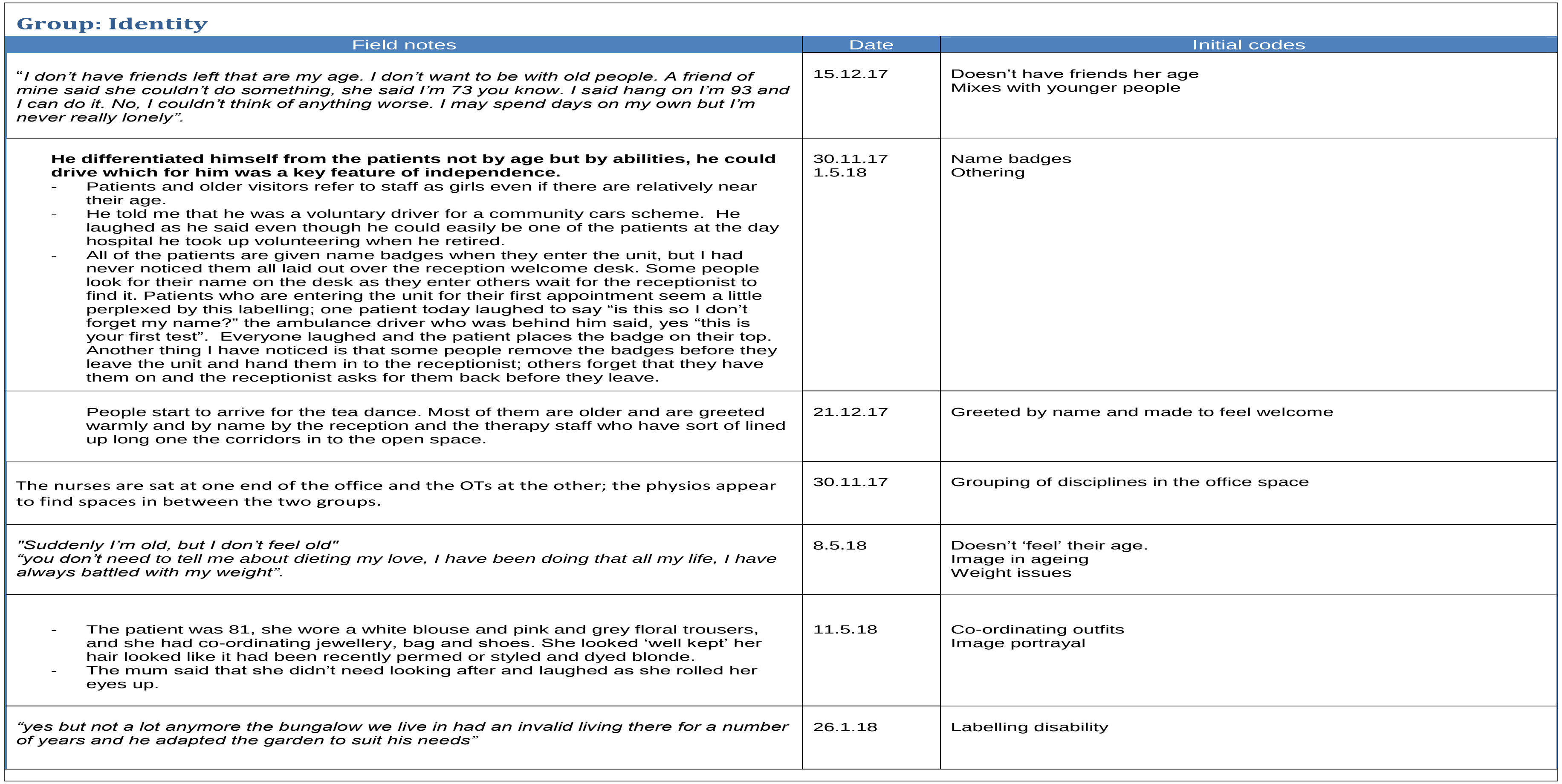
Figure 11: Visual map process of themes

Working in this way, with pen and paper, in such a highly technological environment, felt simplistic at times. My choice of manual analysis was different to many of my peers, what I found fascinating however was that whilst working on the data in the office many people came over and engaged with me, seemingly attracted to the size and bright colours. The tangibility of the work was so different to what many were working with or knew to be academic analysis that they appeared drawn to engage with it. For me, this also reconfirmed, my feelings of connection to the data.

Figure 12: Visual map progression

When these groupings felt representative of the codes they encompassed I transferred them back to computerised text charts adding links to the initial codes and fieldnotes that generated them see figure 12. This gave me a way to quickly access a ***group***, ***code*** or ***fieldnote*** with related themes which I would take forward into the next stage of analysis.

The groups developed from this analytic phase formed the basis of topic areas for conducting the focus groups in phase 2. The aim of phase 2 was to provide additional data to deepen and develop the initial findings in phase 1 and provide an opportunity to further explore the context of identity in this culture. The next chapter with further reflectively outline the processes undertaken in the second phase.



Group: Identity

Field notes	Date	Initial codes
"I don't have friends left that are my age. I don't want to be with old people. A friend of mine said she couldn't do something, she said I'm 73 you know. I said hang on I'm 93 and I can do it. No, I couldn't think of anything worse. I may spend days on my own but I'm never really lonely".	15.12.17	Doesn't have friends her age Mixes with younger people
He differentiated himself from the patients not by age but by abilities, he could drive which for him was a key feature of independence. - Patients and older visitors refer to staff as girls even if there are relatively near their age. - He told me that he was a voluntary driver for a community cars scheme. He laughed as he said even though he could easily be one of the patients at the day hospital he took up volunteering when he retired. - All of the patients are given name badges when they enter the unit, but I had never noticed them all laid out over the reception welcome desk. Some people look for their name on the desk as they enter others wait for the receptionist to find it. Patients who are entering the unit for their first appointment seem a little perplexed by this labelling; one patient today laughed to say "is this so I don't forget my name?" the ambulance driver who was behind him said, yes "this is your first test". Everyone laughed and the patient places the badge on their top. Another thing I have noticed is that some people remove the badges before they leave the unit and hand them in to the receptionist; others forget that they have them on and the receptionist asks for them back before they leave.	30.11.17 1.5.18	Name badges Othering
People start to arrive for the tea dance. Most of them are older and are greeted warmly and by name by the reception and the therapy staff who have sort of lined up long one the corridors in to the open space.	21.12.17	Greeted by name and made to feel welcome
The nurses are sat at one end of the office and the OTs at the other; the physios appear to find spaces in between the two groups.	30.11.17	Grouping of disciplines in the office space
"Suddenly I'm old, but I don't feel old" *"you don't need to tell me about dieting my love, I have been doing that all my life, I have always battled with my weight".*	8.5.18	Doesn't 'feel' their age. Image in ageing Weight issues
- The patient was 81, she wore a white blouse and pink and grey floral trousers, and she had co-ordinating jewellery, bag and shoes. She looked 'well kept' her hair looked like it had been recently permed or styled and dyed blonde. - The mum said that she didn't need looking after and laughed as she rolled her eyes up.	11.5.18	Co-ordinating outfits Image portrayal
"yes but not a lot anymore the bungalow we live in had an invalid living there for a number of years and he adapted the garden to suit his needs"	26.1.18	Labelling disability

Figure 13: Computerised text chart phase 1

Chapter 6 Methods Phase 2: Depth and development

This chapter will detail the method of focus groups used in phase 2 of the study. I explain what a focus group is and why I chose it as a secondary data collection method. I outline the recruitment process for participants and highlight the ethical considerations I made. I discuss the practical elements of facilitating the groups and the analytical processes applied to the data collected. I conclude the chapter by describing how I developed meaningful narratives from the combination of the analysis of both phases and outline how this generated my findings.

After the data collected in phase 1 had been analysed I began phase 2, four focus groups, (patient *n=8*, relative *n=6*, volunteer *n=5*, staff *n=7*) were conducted throughout January and February 2019. I chose to use focus groups as a secondary data collection technique to further deepen and develop the initial findings from phase 1 and expand the exploration of the processes that underpin supporting sense of self-identity in the Day Hospital. During focus groups the data are constructed through the evolving interactions and discussions between participants, where they may confirm or challenge others opinion, this type of back-and-forth discussion can generate deeper and more refined understandings of the topic (Tritter and Landstad 2020).

6.1 Data collection techniques: phase 2 – focus groups

A focus group is a group interview, although some refer to them as discussions in order to differentiate them from individual interviews (Barbour 2007). They are designed to elicit information and perceptions around a focused topic or issue (Guest et al. 2013; Krueger and Casey 2015). Group size can vary between four to twelve people, however somewhere around the median is often considered to be most effective (Holloway and Galvin 2017). They are now one of the most widely used methods in social sciences but are also predominantly used in market research and more recently have gained attention in the media as a way of understanding public opinion on political policies and government campaigns (Smithson 2008; Tritter and Landstad 2020). Whether described as an interview or discussion, the aim of a focus group is to encourage conversation between group members in order to generate dialog around topics and answers to questions (Krueger and Casey 2015; Tritter and Landstad 2020). In comparison to my fieldwork in phase 1, there appeared to be many more practical examples of how to conduct focus groups (Barbour 2007; Smithson 2008; O.Nyumba et al. 2018; Tritter and Landstad 2020). Greenwood et al (2014) highlight that although much of the literature on focus groups emphasise the practicalities of facilitating a group, it is also of great importance to understand the reasons behind wanting to ask questions in a group dynamic.

6.1.1 Choosing focus groups

During individual interviews the researcher generally acts as investigator, often directing the dynamics of the conversation so that focused answers about specific questions can be extracted (O.Nyumba et al. 2018). Contrastingly, during a focus group, the researcher can adopt the role of facilitator, aiming to sit on the periphery of the group but facilitating and encouraging discussion between participants (LeCompte and Schensul 2010; O.Nyumba et al. 2018; Tritter and Landstad 2020). Obtaining group dialogue with similar or contrasting views can allow researchers to gain insights not only into individual’s thoughts and beliefs but also enable a deeper understanding of a groups perceptions and cultural norms on the topic (Barbour and Kitzinger 1999; Barbour 2007).

Guest et al (2013) stresses that the setting and dynamics of the group are integral to the data collected. I was particularly interested in the created culture surrounding identity and frailty, and felt that using focus groups as a method of data collection facilitated an environment where individuals could explore their experiences and opinions of the topic in context to the views of others experiencing the same type of treatment, illnesses or work environment. These attributes made the choice of using focus groups favourable, particularly as they enabled the potential to understand the construction of collective beliefs and identities (Munday 2006) and in this way added credibility to the participant observations in phase 1 (Schensul and LeCompte 2013). The way in which the focus groups were structed were determined following consultation with the PPI group as outlined in Chapter 4.3.1 who stated that they would prefer separate patient and relatives' groups. I decided to run four separate groups, with the provision for further groups should I feel the need once these had been analysed, one each for patients and relatives and another two separate groups for volunteers and staff.

6.1.2 Focus group dynamics and ethical considerations.

Focus groups can be complex to plan and facilitate and are bound by several ethical practicalities (Barbour 2007; Smithson 2008). Unlike some other forms of data collection, the nature of focus groups means that participants identities cannot be hidden from other members of the group (Tritter and Landstad 2020). This can create some potential issues for example, people may feel uncomfortable discussing certain topics in a group environment, or individuals may speak insensitively, or be considered inappropriate by other members of the group. There was an example of this during the patient focus group, where a member of the group commented on how lucky he was not to have multiple sclerosis (MS), which as it happened, I knew one of the other members of the group had.

> *Robert: well I could have this you know, I could have had MS you know, like they don't get better do they, at least I've got hope, at least they said I could get better. Or should get better, but they've got nothing have they.*
>
> *(Taken from Patient focus group line 688-690)*

Although the participant with MS didn't verbally respond to his comment, she looked at me, rolled her eyes and shifted uncomfortably in her wheelchair. I felt unnerved knowing she had the condition to which he had referred. She showed no signs of significant distress, so I chose not to intervene at this point as the conversation continued. Others in the group appeared to interpret Robert's comment to mean that he was trying to be positive about his own condition by comparing it to others he considered less fortunate, to which they agreed. As I describe later in this thesis, this agreement further reinforced processes which I had observed in phase 1. After the focus group I did check in with the participant with MS to acknowledge this and she was not distressed as she recognised that he may have been unaware of her condition. I used this experience moving forward, to highlight in other groups the potential differences the members had and to be mindful when discussing specific conditions that others may be experiencing.

Another ethical consideration I faced was facilitating the dynamics of the groups. One of the things I don't think I fully anticipated, on reflection quite naively, was how many of the participants used the focus group context to retell, reflect and explore their own life narratives. Tritter and Landstad (2020) note how focus groups can hold space for personal discovery and connections with others having similar experiences. Each of the groups appeared to experience this in different ways which called for varying facilitation skills. For example, individuals in the relative group comparatively spend a lot of time in monologue, explaining their situation and caring role, discussion between individuals needed to be encouraged, yet I felt conscious that people also needed to have their story heard so that discussion could continue. This type of observation was also important to note as part of the data, as it may indicate for example that relatives don't feel heard and had a greater need to tell their story. In this way observational data regarding the interactions and behaviours within the focus groups could be as valuable as the content itself (Munday 2006). In the volunteers' group many of the participants spoke over each other and often broke off into individual conversations. For me these examples highlight how participants will bring their own agenda to an interaction and often talk about what feel most important and relevant to them regardless of the topic guides (Karnieli-Miller et al. 2009).

The topic guide (Appendix 6) was developed from the analysis of phase 1 data, in order to bring focus to areas that appeared important and of interest, with the hope of deepening my understanding of them. I structured each of the focus groups in a relatively loose interview style, developing a topic guide of questions that I hoped would yield powerful narratives. I used open ended questions such as *"how did the environment of the Day Hospital make you feel?"* and avoided dichotomous yes/no questions where possible. I used "think back" questions in order to prompt people to reflect on events and experiences and enable those who may have been less involved in the discussion to have a discuss a specific experience (Krueger and Casey 2015), for example; "think back to when you first came in to the Day Hospital, what did you feel? Was there anything you noticed in particular?".

The contribution of each of the focus groups added depth to my initial phase 1 analysis, because of this I was able to evolve my focus in certain areas of interest as the groups progressed. This meant that the topic guide changed slightly in each subsequent group as certain topics appeared to become more distinctly significant than others. Whilst the guide for the focus groups were constructed in this way, it was also important to let the conversation flow to let the group engage with themes that I had not identified in phase 1, as facilitator I needed to find a balance between enabling this flow of conversation and maintaining focus on the overall topic, the process of which I discuss later in this chapter.

6.2 Focus group participants: phase 2

6.2.1 Identification of research participants: sampling strategy

Once phase 1 had been completed I focused on recruiting participants for phase 2, although participation in phase 1 appeared generally accepted, I was unsure of what to expect when it came to participation in the phase 2 focus groups. When choosing a sampling strategy, the overall research question is of great importance (Barbour 2007). I used a broad but purposive approach to sampling potential participants for the focus groups. Purposive sampling describes the process of selecting the sample based on a specific criteria in order to maximise achieving the research aim (Holloway and Galvin 2017; Fetterman 2019). Key to ethnographic principles is the understanding of cultural knowledge and how this is socially constructed within a particular group (O'Reilly 2009; McGarry and Mannik 2017; Kirner and Mills 2019), therefore to add trustworthiness and credibility to the data, the goal is to have a variety of key informants, this means those who hold knowledge about the culture and are willing to engage in revealing such knowledge (Moser and Korstjens 2018). This meant that I needed to access informants from the four key groups I highlight in phase 1. However, from the initial analysis of that phase it became evident that many of the potential participants were already 'stretched' both mentally and physically and I recognised that participation in a group interview required greater commitment than being observed. I was also conscious that to illicit meaningful interaction in a timely manner, there was a limit to the number of participants that I could facilitate. Participants were actively recruited in differing ways depending on their group membership, and against the sampling criteria outlined in Table 6.

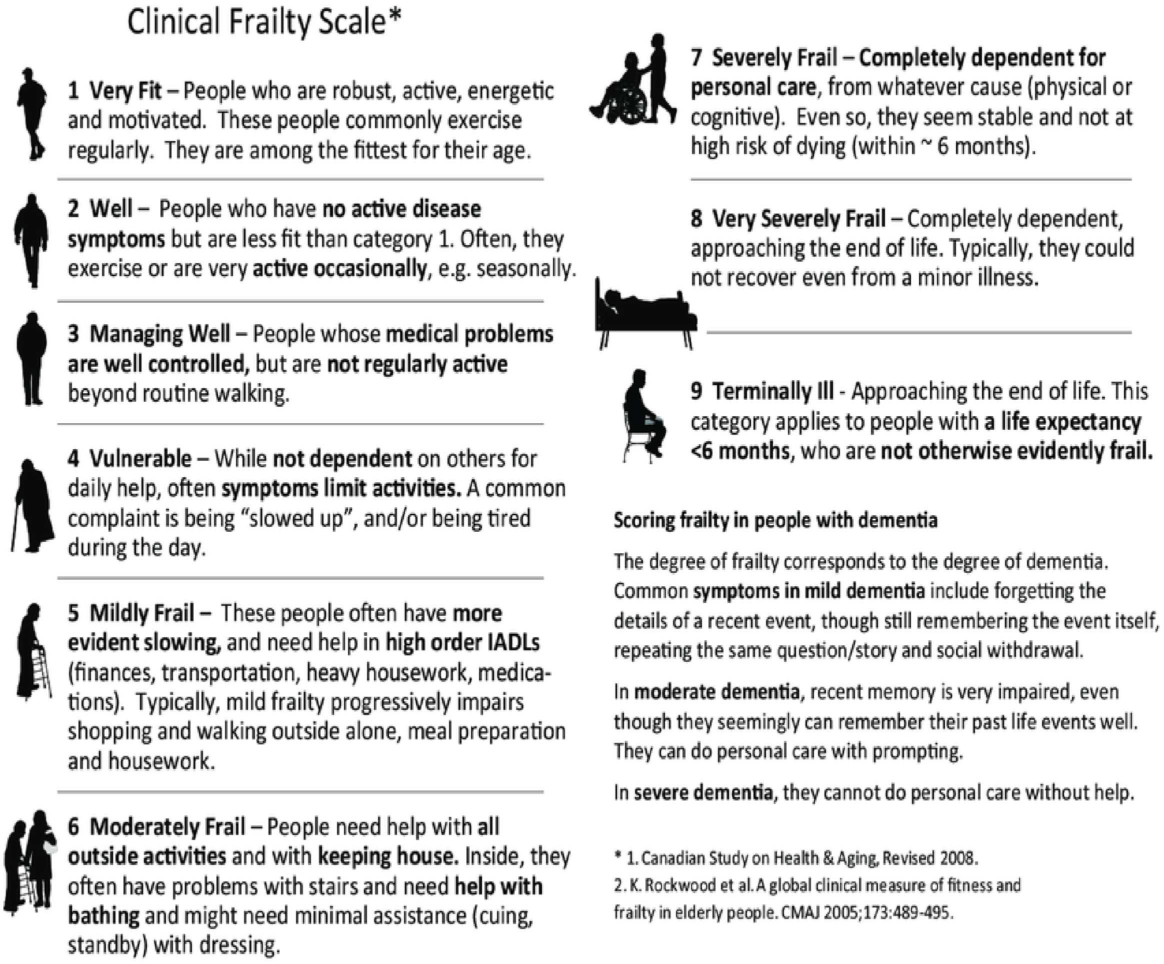
Table 6: Sample inclusion criteria phase 2

Participant Group	Inclusion criteria	Exclusion criteria
Patients	Patients currently receiving treatment within Christchurch Day Hospital Patients with a Clinical frailty scale score of 5 or above Patients aged over 65 years Male and female Any ethnicity	Patients with a Clinical frailty scale score of 4 or below Patients aged under 65 years Patients unable to participate in group discussions due to cognitive deficits which would likely cause distress to the patient or members of the group. Those unwilling to participate. Lacks capacity to consent for themselves
Relative/carer	Relative or carer of a patient who meets the above patient inclusion criteria and has agreed for their relative/carer to take part in the study.	Relative or carer of a patient who meets the above patient exclusion criteria Relative or carer of a patient who has declined permission for them to be contacted.
Volunteers	All volunteers at day hospital.	Any volunteer who declines to participate
Staff Any member of staff who is permanent, rotational or bank staff. And who is part of the core services employed by the Day Hospital which include:	Clinical Leaders/Management Staff Doctors Nurses Physiotherapists Occupational therapists Health care assistants Therapy assistants Administrative staff	Any staff member who declines to participate

6.2.2 Identifying the older person with frailty.

Throughout the study I was conscious of the risk of homogenising and labelling people with frailty. Part way through the study I realised that I had been describing participants as' frail older people' when I meant older people with frailty and began to change the construct of my descriptions. Many of the patients referred to the Day Hospital were living with frailty, and nearly all were vulnerable to frailty due to symptoms and conditions which limit their activities of daily living. During my initial discussions with the staff in the planning stage, it came to light that although frailty was recognised as a concept in the assessment of patients within the Day Hospital, objective levels of frailty were not documented in any standardised fashion. Although initially surprised at this, I came to believe that this further reinforced the importance of this research in exploring understandings of frailty within the Day Hospital.

In chapter 1, I discussed the negative connotations associated with labelling someone as frail, associations which were actualised in the findings of this study. I spent time therefore, internally debating how, without an established frailty tool, I or others would identify those with frailty. As I described the Day Hospital assessments utilise the Comprehensive Geriatric Assessment (CGA). It is predominantly an assessment and treatment tool and does not independently attribute a level of frailty or frailty score to a patient. I did not want to add to the homogenisation of people with frailty, yet I needed to be able to identify people living with frailty in this population. Although not routinely used in the Day Hospital, the Rockwood Clinical Frailty scale (CFS) (Rockwood et al. 2005), was used in more acute areas within the trust and the Day Hospital had easy access to it. With Day Hospital management we agreed that this would be a quick visual frailty instrument, that staff could use to easily identify study participants. As described in chapter 1 the CFS was specifically developed as a measurement tool for frailty in an outpatient setting (Rockwood et al. 2005), Figure 14 shows the CFS visual prompts with descriptors.



Clinical Frailty Scale*

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 Managing Well – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

Figure 14: Clinical frailty scale descriptors

Having considered other options such as the Frailty Phenotype (Fried et al. 2004), I felt that the CFS was the most appropriate measurement tool to use as it could be used by the treating therapists based on the information they took within routine assessments already completed as part of the patients journey within the Day Hospital, this meant that there was no additional intervention for the patient or work for the staff. This did mean however that I somewhat relied on the subjective opinion of the therapists to identify potential participants that fitted the sampling criteria.

6.2.2.1 Recruitment of patients and relatives

Patients who were identified by their therapists as meeting the frailty inclusion criteria outlined in Table 6, were informed about phase 2 focus groups by the therapist. If the patient was interested in participating, they were given a phase

2 PIS (Appendix 7) and asked if they would agree to be contacted directly by myself. If permission was granted, I contacted the person the week after in order to discuss the study further, answer any questions they had and see if they wanted to proceed. If they agreed to take part, I confirmed their eligibility against the sampling criteria, and posted a letter of invitation to attend a focus group. Additionally, I asked the patient if I they had a relative or carer who may like to take part in a separate group. If they did the therapy team would approach the relative and give them information about the study, and their details were also passed to me. Some patients declined to take part but had relatives who wanted to and were included if the patient agreed we could contact them. Once an individual had agreed to participate, I gave them a courtesy call the week of the focus group in order to clarify any queries, confirm their attendance and arrange transport if needed. *n=13* patients were interested in participating and given a PIS, of them *n=3* declined by contacting me and *n=2* did not respond, with *n=8* enrolling. n=9 relatives were given PIS, with *n=6* enrolling.

6.2.2.2 **Recruitment of volunteers and staff**

I personally informed the volunteers about the focus groups and if interested gave them a PIS to consider. I returned the following week to follow up and answer any questions. If they chose to take part, I gave them a letter of invitation to attend a group. Again, a week prior to the groups I contacted participants to check they wanted to continue and answer any queries. *n=7* of the 10 volunteers wanted to participate however *n=2* withdrew interest due to other commitments. Of all the groups the volunteers appeared to be the hardest to recruit, this was not due to lack of interest, rather that many of them had very active and routined social lives and it was difficult to find a time for the focus group that suited all of them. This experience became more significant once the data had been analysed as it added further credence to one of the findings.

I informed staff of the focus groups during their weekly team meetings. After these meetings I distributed the staff PIS via email to all staff and left some paper copies in the therapy office in a prominent place for people to read and consider. *n=9* members of staff contacted me after these meetings expressing an interest in participating in the study. I again visited the Day Hospital to discuss with those interested, answering any questions and gave them consent forms. I agreed with management that the staff focus group could be conducted within the usual working hours of the unit which I think enabled more staff to participate. Of the 9, *n=1* was unable to attend due to external commitments.

6.2.3 Setting the Scene: Tone and group expectations

Before the groups started the note-taker and I set up the room, Krueger and Casey (2015) note the importance of ensuring the environment of the focus group is conducive to open conversation, relaxed and inviting with little outside distraction. I decided to hold the groups in a room within the Day Hospital. I choose this as I felt people would find it a familiar setting and on a practical level was easy for people to get to. One of the walls in the room had a long glass window which ran the width of the room which we covered so no one could see in and reduced distraction. I also provided light refreshments which I placed in the centre of the table, I felt this portrayed a relaxed and informal space. Chairs were placed around the table so that the group were facing one another. As participants arrived, I met them in reception, or in the office for the staff, and walked them to the room where the note-taker encouraged them to get a drink and something to eat. I took this opportunity to reintroduce myself and engage in informal conversation which enabled me to get an initial sense of their mood and personality. As more people arrived both myself and the note-taker used the time to start to develop rapport but also observe the groups initial interactions with each other. Generally the atmosphere was relaxed and jovial, there was a number of funny movements as people found their places and got their chair leg stuck or knocked their tea over, and I noted these as very human reactions and interactions which appeared to create a sense of equality which was apparent across each of the groups. This period of ‘chit chat’ and settling prior to the start of the focus group was a good time for me to get a sense of who might be quiet and need encouragement and also identify those that may have a more dominant personality that may need moderation in a group context (Guest et al. 2013). One example of this was in the patient group which I describe below.

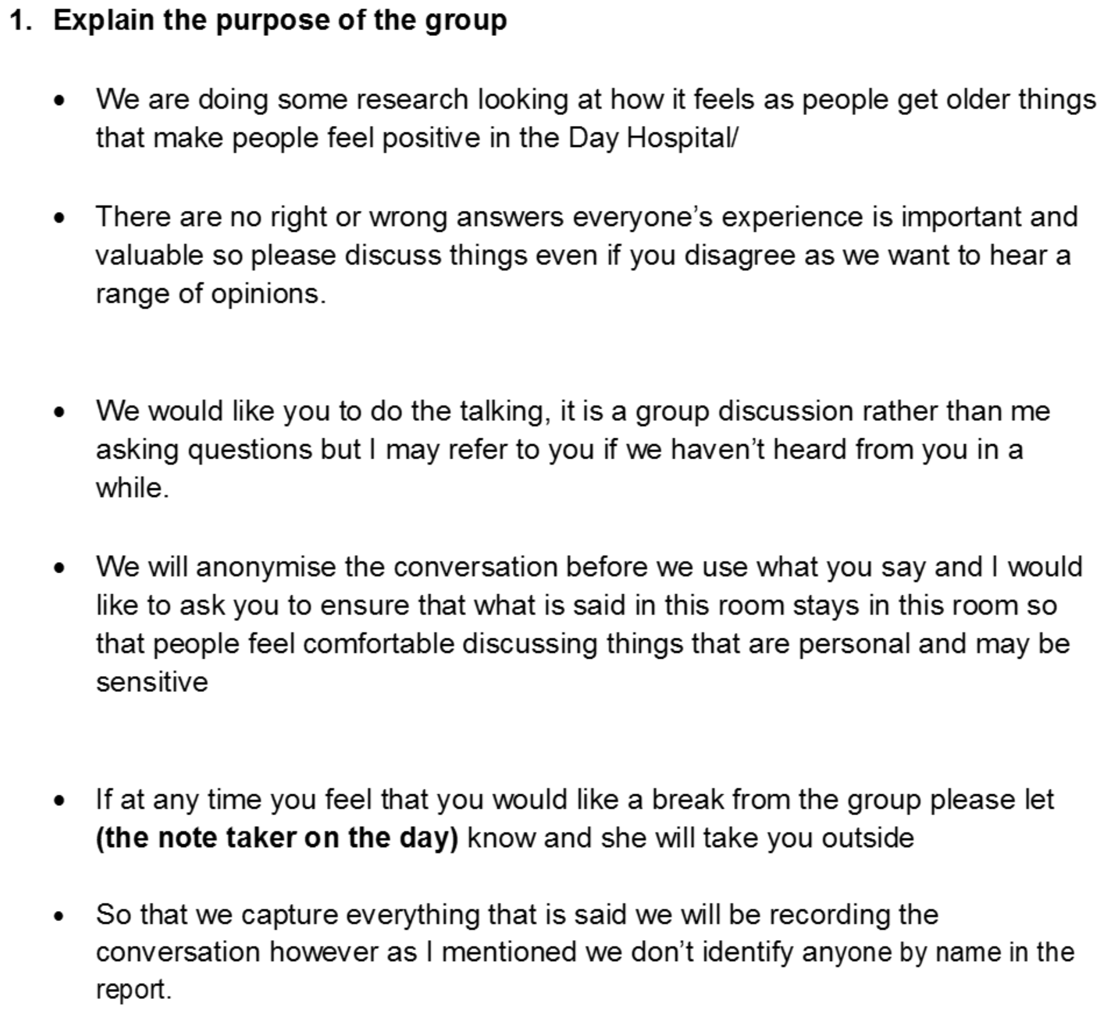
> *Anne arrived at reception walking very slowly with a walking aid, she was a short, slight woman with grey curly hair and hunched spine which meant that she walked with her head facing down, even when I spoke to her to introduce myself she seemed unable to lift her head to speak and she had a very quiet voice. We walked to the room and I helped her sit where she chose. Throughout the ten minutes or so that we were waiting for people to be seated and get a drink Anne didn't speak to anyone, she appeared to have quite significant arthritis in her hands and struggled somewhat to sign the consent form. She also quietly asked me to write her name on her badge, whereas other had written their own. At this point I had some reservations as to how much Anne would be able to participate in the group and I sensed these thoughts were shared by the note-taker who looked concerningly in her direction. Once everyone seemed settled, I began to explain the purpose, answer any questions and offer reassurance. The group overall was quite dynamic and exuberant in their discussion, for the first ten minutes Anne said barely a word, it was hard to see if she was listening even, as her physical appearance made it difficult to see her face. I started to look for what I call 'hooks' that I could use to bring her in to the conversation. Then suddenly she found her own hook and started to engage. From that moment forward Anne provided some of the most considered narrative about herself and identity. After the group, both the note-taker and I shared with each other how our perceptions of Anne differed to the reality she gave.*
>
> *(Note from PFG January 2019)*

This experience happened in the first focus group and emphasised the need for reflexivity, that even when you believe yourself to be aware of your preconceptions regarding frailty and identity, and feel sensitive to the issues, both myself and the note-taker were so easily challenged by our own presumptions.

6.2.4 Running the focus group

Each of the groups lasted between 45 and 75 minutes and were audio recorded. I also enlisted the support of a note-taker, their role was predominantly to capture an overall sense of the group and the discussion as well as noting anything they considered may be of importance. During the focus groups, the note-taker sat within the room, but outside of the group and produced their own set of notes which we discussed together immediately after the group finished. We discussed issues we both individually felt emerged as key features of each of the groups as well as themes that arose and I used this contribution as part of my analysis. Additionally, the note-taker was available to support participants should they need to leave the discussion for any reason and looked to ensure recording equipment was set up correctly.

Before the focus groups began, I explained the purpose of the group and suggested ground rules to support a feeling of safety and to ensure people were aware of our roles as moderator and note-taker. Figure 14 gives an example of the prompts I used to explain the ground rules.



1. Explain the purpose of the group

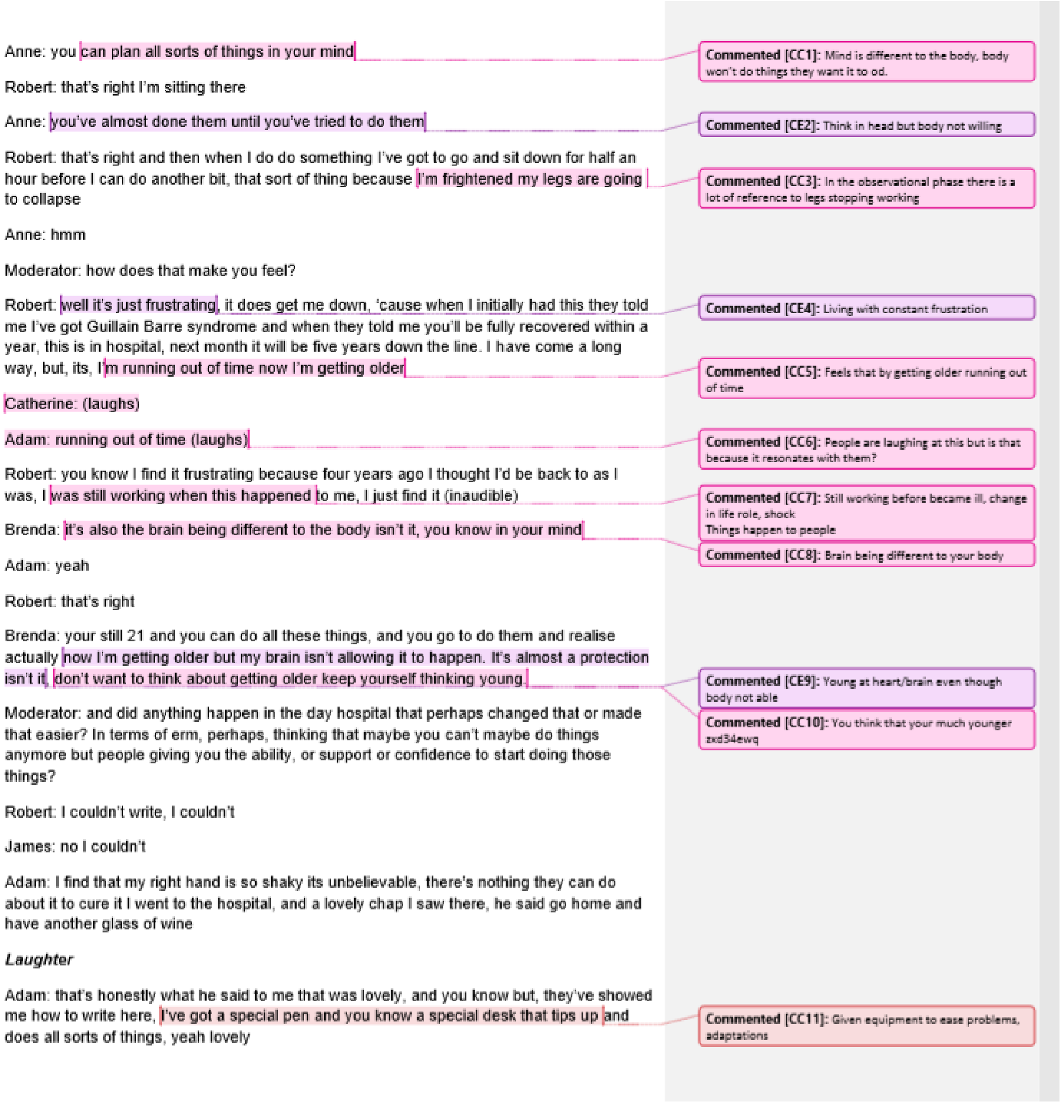
- We are doing some research looking at how it feels as people get older things that make people feel positive in the Day Hospital/
- There are no right or wrong answers everyone’s experience is important and valuable so please discuss things even if you disagree as we want to hear a range of opinions.
- We would like you to do the talking, it is a group discussion rather than me asking questions but I may refer to you if we haven’t heard from you in a while.
- We will anonymise the conversation before we use what you say and I would like to ask you to ensure that what is said in this room stays in this room so that people feel comfortable discussing things that are personal and may be sensitive
- If at any time you feel that you would like a break from the group please let **(the note taker on the day)** know and she will take you outside
- So that we capture everything that is said we will be recording the conversation however as I mentioned we don’t identify anyone by name in the report.

Figure 15: Ground rules for focus groups

6.2.5 Phase 2 Analysis: Groups as units of analysis

As previously outlined the groups derived from the analysis of phase 1, formed the basis of topic areas for conducting the focus groups. The aim of the focus groups were to provide supplementary data to deepen and develop the findings in phase 1 and provide an opportunity to further explore the context of identity in this culture. With this in mind, the focus group data were analysed in a separate process from phase 1 data but using the insights that phase 1 analysis had provided.

I first anonymised and transcribed verbatim the individual focus group audio recordings, this process took me several hours listening over the discussions. Once transcribed I re-read the transcriptions several times, annotating initial thoughts, which I named memos and codes in the margins. The memos were an analytic record of my thought process and I began to make connections across the data. Anonymised transcriptions were also sent to the supervisory team and they followed the same process, we then met as a group to discuss and consider the data and codes identified. Each focus group discussion was independently analysed in this way. Figure 15 shows an example of these initial memos and coding on a transcription.



Anne: you can plan all sorts of things in your mind

Robert: that's right I'm sitting there

Anne: you've almost done them until you've tried to do them

Robert: that's right and then when I do do something I've got to go and sit down for half an hour before I can do another bit, that sort of thing because I'm frightened my legs are going to collapse

Anne: hmm

Moderator: how does that make you feel?

Robert: well it's just frustrating, it does get me down, 'cause when I initially had this they told me I've got Guillain Barre syndrome and when they told me you'll be fully recovered within a year, this is in hospital, next month it will be five years down the line. I have come a long way, but, its, I'm running out of time now I'm getting older

Catherine: (laughs)

Adam: running out of time (laughs)

Robert: you know I find it frustrating because four years ago I thought I'd be back to as I was, I was still working when this happened to me, I just find it (inaudible)

Brenda: it's also the brain being different to the body isn't it, you know in your mind

Adam: yeah

Robert: that's right

Brenda: your still 21 and you can do all these things, and you go to do them and realise actually now I'm getting older but my brain isn't allowing it to happen. It's almost a protection isn't it, don't want to think about getting older keep yourself thinking young

Moderator: and did anything happen in the day hospital that perhaps changed that or made that easier? In terms of erm, perhaps, thinking that maybe you can't maybe do things anymore but people giving you the ability, or support or confidence to start doing those things?

Robert: I couldn't write, I couldn't

James: no I couldn't

Adam: I find that my right hand is so shaky its unbelievable, there's nothing they can do about it to cure it I went to the hospital, and a lovely chap I saw there, he said go home and have another glass of wine

Laughter

Adam: that's honestly what he said to me that was lovely, and you know but, they've showed me how to write here, I've got a special pen and you know a special desk that tips up and does all sorts of things, yeah lovely

Commented [CC1]: Mind is different to the body, body won't do things they want it to od.

Commented [CE2]: Think in head but body not willing

Commented [CC3]: In the observational phase there is a lot of reference to legs stopping working

Commented [CE4]: Living with constant frustration

Commented [CC5]: Feels that by getting older running out of time

Commented [CC6]: People are laughing at this but is that because it resonates with them?

Commented [CC7]: Still working before became ill, change in life role, shock
Things happen to people

Commented [CC8]: Brain being different to your body

Commented [CE9]: Young at heart/brain even though body not able

Commented [CC10]: You think that your much younger zxd34ewq

Commented [CC11]: Given equipment to ease problems, adaptations

Figure 16: Initial coding transcription phase 2

Once the team felt that the transcripts had been thoroughly reviewed, I created a coding table which listed the section of transcription, associated memos and code. Each of the focus groups were allocated a colour: orange for patients, pink for relatives/carers, green for volunteers and blue for staff. I printed the coding tables on the relevant colour paper and again used a sorting method to group the codes. Because of the size of the data set I attached these codings to a large wall, where we were able to stand back and review the grouping structure, as can be seen in figures 16, 17 and 18.

Again, these groups were not fixed and we spent some amount of time rearranging them until we reached a sense of placement and relatedness.

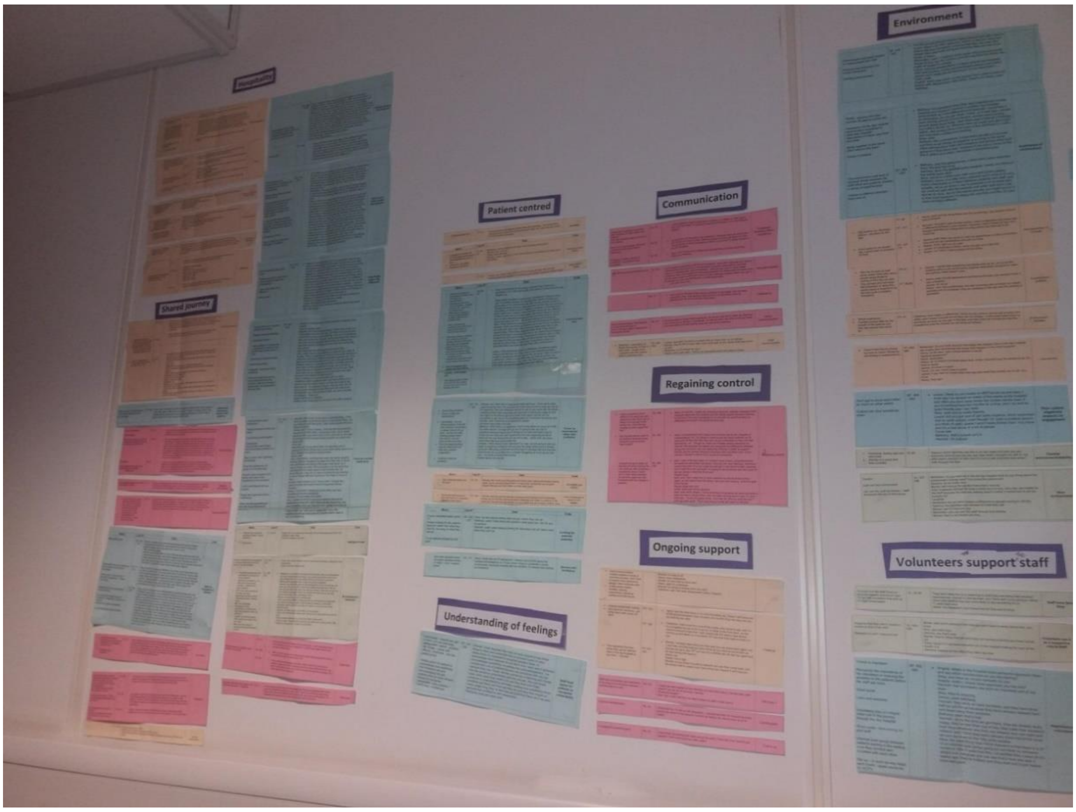


Figure 17: Focus group data analysis process

Figure 18: Focus group data analysis process

Figure 19: Focus group data analysis process

6.2.6 Creating meaningful narratives

The aim of these analytic processes was to bring together data from both phases in order to create meaningful narratives that answered the aims of the research. The identified themes from the two phases were brought together at this stage to form a conceptual diagram, as I had used in the phase 1 analysis. Conceptual diagrams enabled me to map out relationships and structures that came from the data (LeCompte and Schensul 1999), through this process I was able to develop meaningful narratives that represented my observations and experiences within the field and retold the participants stories. The final research account, detailed in the following three chapters, is rooted in the data generated and constructed within field.

6.3 Reflexive research practice

The role of reflexivity is a central premise within qualitative research and holds particular importance within ethnography (Pellatt 2003). However, within the literature it is seen as a concept notoriously difficult to articulate and unravel (Doyle 2012, Dowling 2006, Palaganas et al. 2017). In its simplest terms, reflexivity can be understood as our human capacity to make sense of our social existence (Eriksson et at. 2012). Reflexivity entails self-awareness of our activity within the research process and our recognition that as researchers, we are part of the world we study (Palaganas et al. 2017). The aim of researcher reflexively is also dependent on our epidemiological assumptions; where it may be used by an objectivist to acknowledge their prior knowledge and distance this from the data, my view was to use reflexive practices to understand the way in which my claims are socially constructed and therefore enhancing their value (Haynes 2012). Conducting research within a field changes us in multiple ways. Reflexivity can be used to acknowledge how these changes shape us and affect the research process (Palaganas et al. 2017).

In chapter 3 I discussed my positionality within the field and acknowledge the significance of this on the process and construction of the findings to be presented. Reflexive research practices require one to operate on multiple levels through acknowledgment of their involvement in the process and product of the research, at both personal and epistemological levels (Etherington 2004, Koch and Harrington 2002). It is therefore characterised by ongoing critique of one's position, self-appraisal and politics of the environment (Koch and Harrington 2002).

Allen (2004) highlights several processes that can demonstrate reflexive research and augment the rigor of a study, as I discussed in chapter 4. Reflexivity has been described as more of an ideological concept than a list of specific actions (Markham 2017), however in this section I will detail the ways in which I worked reflexively, how I viewed the field of study through my philosophical lens, how my position affected the social world of the Day Hospital and how I was affected by that social world.

6.3.1 Reflexivity awareness within the field

As I entered the field to begin my research I came with a strong awareness of how my presence would influence the interactions and actions that I observed. In order to capture this, I decided to start a reflective journal alongside my fieldnotes, this journal became a place where I could document my thoughts and feelings regarding my research activity, and ultimately became an essential tool when analysing my data. The journal became a format for me to continually assess my position and evaluate my presence. At the start of the study I was aware that my presence may feel threatening to those around me; at this time documentation of my relationships and interactions with the staff seemed to dominate my journal reflections. I recognised that my relationships with the staff would be structured around how they viewed both me as a person and my 'motives' for being there. In chapter 3 I note how I appeared to be viewed in multiple contexts, as an academic, a nurse, a researcher, and I feel later in the study as a colleague and perhaps even friend. In the following chapters I note occasions where 'jokes' were made regarding my presence in the Day Hospital, the journal became a place where I could reflect upon these comments and explore the reasons and emotions that were generated by them. Although none of the staff opted out of the study, some of them appeared less interested in engaging with me. This may have been due to them feeling that I was critiquing their practice, and as I read back through my journal I became more mindful of attempting to alleviate this thought process for them. As time progressed the sense of outsiderness that I initially felt lessened. I worried however if this was a 'bad' sign, had I become too immersed in the culture that I risked becoming blinkered to the social world around me? Through reflexive practice however I came to understand that my feelings of insiderness and acceptance within the group were more likely a construct of the cultural practices that the group possessed.

Journaling also enabled me to maintain my focus when needed and consider observations through my epistemological lens more clearly. There were times where I felt overwhelmed with the amount and complexities of the data I collected, notions of needing to continually consider myself in the data brought feelings of confusion and lack of clarity at times. During these periods I used my journal to add shape to seemingly shapeless thoughts. I would head my page with the words "A new day", for me this prompted me to open my mind to the concept of multiple truths, and not to be concerned by the fact that one day was different to the next. In this way I came to accept my data as it stood, constructed on that day through the interaction of myself and the different social actors that created it. By reading my journal alongside the data collected it appeared that my own feelings of acceptance and security within the group were similar to those emerging from the experiences of people using the service. Rather than adding doubt to the legitimacy of my thoughts and observations, this reflexive practice came to add robustness to the observations and narratives of other actors within the field. From an epistemological viewpoint I had to remind myself that there were limits to what we can know with any certainty, and that it was important to acknowledge those limits when interpreting my observations (Orellana 2019).

Additionally, I discovered the concept of mindfulness reflexivity (Orellana 2019). Mindfulness is an awareness of the present moment, where one can be present in that moment without judgement (Sedletchi 2019). Ethnography calls for us to see and understand others in their own worlds, but we must step out of our own worlds to do so (Orellana 2019). By utilising techniques of mindfulness in conjunction with my journal; for example; being conscious of my senses, my emotions and my body within a situation, and documenting this, I was able to demonstrate my immersion within the field and draw upon this within my analysis and interpretation. Reflexiveness enabled me to question why I thought something, and why I felt things, sometimes things which I had never considered. For example, what it meant to me by the way someone looked or smelt, what thoughts those experiences brought to my mind, and how that may have influenced my actions and interpretations. Through the process of mindfulness, I became more attuned to the multiple identities that I identified with throughout the study and developed an awareness of what may activate these identities within a given situation (Orellana 2019). Throughout the findings chapters I aim to demonstrate these reflexive thought processes.

6.3.2 Personal awareness

I considered whether to separate this section from the previous ‘awareness within the field’ for some time, the complexities of positionality in ethnography call in many ways for the personal and fieldwork affects to be one and the same. However, I think it is important to document here some personal insights to give further context to the findings that I will present later, and how these experiences have developed my understanding of this study and my research practices as a whole.

In addition to considering the way in which others may have viewed me I also needed to consider how I viewed myself. In many ways I felt that my position as a nurse graced me with acceptance in to the Day Hospital from the perspectives of managers, staff and patients. I was aware however that my view of myself, my being, should be noted as I believe this to have played a role in the construction of these findings. I feel that I generally portray myself as a ‘laid back’ person, I enjoy people and listening, and I feel that these qualities served me well in my interactions. I do however hold self-doubt, as do many of us, and on reflection I can see evidence of this within my journaling. In nursing practice, we are surrounded with rigidity and structure, our notes must be accurate, and our practice based on evidence (Paans et al. 2011). At times I struggled with the concept of ‘accuracy’ in my data, yet I came to understand that I was not searching for accuracy, rather truthfulness to the participants way of being through the data collected. I came to accept that my role as the research instrument was to reflect my interpretation of the participants truth, yet this truth could not be considered accurate in the sense that it was interpreted through my personal lens.

Through journaling I was able to question my intentions and concerns daily, take in to account my own emotions and those of the social world around me. Through these processes I experienced moments of enlightenment and clarity, an example was during the focus group interviews where I made assumptions about a participants' capabilities to contribute based on their appearance, mannerisms and behaviour. These assumptions were also shared by the note taker and it wasn't until after the group had finished that we sat for a few minutes processing what we had experienced. The woman who we had both thought would not be able to engage with the group actually brought some of the most valuable and fascinating contributions. I noted in my journal my thoughts and anger at myself for making these assumptions, especially as I considered myself to be open to capabilities of all. This moment profoundly affected me, it made me realise the ease with which we judge others and how these judgements can so simply influence our perception of a person's capabilities. I believe that these experiences positively affected my position in the field, and my deeper exploration of how capabilities were viewed within the Day Hospital. Additionally, it impacted upon my own clinical practice. This awareness of my preconceptions, I feel, positively influenced my interactions with other patients. I heard the importance of feeling listened to and acknowledged, to be present with the person and recognise the human connections we share.

Finally, I must acknowledge my own life experiences which cannot be separated from these reflections. During this study I became a carer for both of my ageing parents, the personal experiences of this not only enabled me to empathise with the complexities that patients and carers within the Day Hospital faced, but I feel, enabled me to have a shared perspective with some within the field. On reflection this may have influenced some of the discussions I had with participants. I would openly share my experiences of caring for my parents with others on what felt like a human level, I wanted those conversing with me to know that I was not a remote researcher, totally naive to some of the challenges that they faced. Although I pondered many times on how remote I should be from the participants, I feel that these experiences added a richness to the findings. My openness enabled trust to quickly develop within the relationships and I believe, my reciprocity in giving of my own personal narrative opened opportunities for data that might otherwise have been lost. I lived with uncertainties in my own world, my own vulnerabilities and felt responsibility for the vulnerabilities of others. My parents' health felt precarious but reflected much of the observations and narrative of others within the Day Hospital. Although an 'outsider' within the Day Hospital, there were moments where I was brought 'into the fold' and felt cared for on a personal level, and I found myself reciprocating this care. Although I enjoy people, I am not a natural hugger, I feel awkward in this situation and out of place, but I noticed that I started to become more accepting of these physical interactions, and this is something that has continued past the data collection. This journey is not one that can be easily described in words and is still something I am likely still processing however, my hope is that my writings in the following chapters may portray some of the emotions and experiences I felt.

The process of reflexivity involved me considering how my thinking came to be, and how my pre-existing concepts of the world can be revised in light of new understandings (Haynes 2012). Through reflective journaling and the processes of mindfulness and presencing, I can reflexively represent the findings of his study in the context of my presence as the research instrument within the field.

6.4 Chapter summary

The previous three chapters detail the ethnographic methods I used to collect and analyse the data in this study. I have discussed the ethical considerations and practical dilemmas that I needed to consider and highlighted my position within the process of data collection and analysis. In the following three chapters I present the study findings as three overarching themes.

Chapter 7 The Study findings

The next three chapters present the findings of this ethnography based on the analyses and integration of data collected from both study phases. These findings were developed over several months of participant observations and deepened and substantiated by the addition of focus group data which illuminates the multifaceted and complex nature of how identities are constructed by individuals and groups. I looked to understand what may contribute to these identities and found that older people entered the unit with a large burden of losses which manifested in a variety of ways but were often linked to fear. Older people, and others observed, held socially constructed ideas of what a hospital is and how others, both their peer groups and healthcare workers, may perceive them. Through the iterative process of sense making and immersion in the data three overarching themes arose. For me these seemed to follow a journey through the unit, and I have therefore thematised these findings in to three chapters; *At a loss, Fostering a hospitable environment*, and *Working within a supportive culture*, in order to assist with sense making of the findings. Thick description of events and interactions are used to give context and comprehension to what they illuminate (Mills et al. 2010).

7.1 Contextualising the findings: reflections on conducting fieldwork

In the NHS conducting healthcare research is common, and I discovered that the Day Hospital staff had taken part in a few research studies in the past, mainly linked to falls interventions. I sensed however that my research was different to their previous experiences where, in many ways, they were the intervention under examination. It felt intimate, and personal, and I had an acute awareness of this whilst in the field. In chapter 4 I touched upon comments that were passed regarding my presence, and although I felt my presence was generally accepted I had a continual awareness of my perceived position. Throughout the findings I have provided reflexive points in order to demonstrate both the complexities of the findings and my position as researcher in their development. In chapters 3 and 6 I have outlined my considerations in relation to my positionality within the study, in line with my epistemological perspectives, I have acknowledged my influence through my presence in the field on the construction of these findings and they should be read within this context to represent my interpretation of the culture within the Day Hospital.

Bringing these findings together and within context to the wider literature I came to visualise the experience of living with frailty as metaphorically being comparable to walking a tightrope. In this image each of us have a tightrope we walk along throughout our lives, these tightropes are constructed of strands of fibres, where each fibre represents an element of our being; our partners, friendships, work, health etc. I present this metaphor as a visual image in chapter 9.5. to help make sense of the experiences and processes identified within these findings.

This first chapter of these findings reveals the experiences of people living with frailty, navigating their way through the Day Hospital service whilst simultaneously re-balancing their identities and negotiating changes in the context of their condition and environment.

7.2 Findings Section 1 - At a loss – balancing losses in frailty

This first section details how the identities of older people with frailty are constructed, in part, by several losses, particularly at the start of their journey through the Day Hospital. I describe how older people use functional ability rather than chronical age to define themselves and others, and how they invest time and energy into negotiating and balancing risks, as they increasingly feel restriction imposed by others. Consequently, fear of loss of functionality and independence appears to be a major contributing factor in their identities and affects how they not only see themselves in a wider social context, but also how they present themselves to others. These losses were based around losses in physical and cognitive functionality, independence, agency and social identity, which will be discussed in more detail below.

7.3 Identity- loss of functionality not age

Most patients had been referred for treatment at the Day Hospital after a specific health event which could range from a minor fall to a stroke, however there was a sense that these acute events sat on a background of more complex losses. Decline in physical functionality was one such loss which became central to the focus of many patients and their relatives. For some this decline had progressed slowly over several months or years, for others it arrived suddenly but for all there appeared to be an element of surprise or shock at its arrival.

Loss of driving or anticipating this loss appeared to be a key trigger for anxiety in older people and loss of wider social interaction and subsequent loneliness. For example, during a treatment session between a nurse and a female patient, the patient spoke of how she meets up with some other women at the golf club for lunch once a week which she drives to saying

"That's all we worry about really, us women, is the day they tell us we can't drive. I will be devastated. It's our lifeline. I don't know what I would do to be honest"

(Taken from field notes 8th May 2018)

The use of the word *devastated* highlights the significance of this fear to her sense of self and the term *lifeline* suggests she sees driving as her means of survival in her current situation.

She spoke a lot about getting older and how it felt "*like a shock*" to be her age, "*suddenly I'm old but I don't feel old*". Although fears associated with losing her driving licence or falling over in her house when she was alone were evident, she also related these fears within a different pace of life compared to both myself and the nurse in the room. For example, she commented

"That's the main worry really now days, I don't know what I used to worry about when I was your girls ages. I don't know how you have enough hours in the day to do everything, you go to work, you have children and keep a house, I get tired just washing up but I can take all morning if I need to, you can't".

(Taken from field notes 8th May 2018)

This suggests that she feels more worried about things now in her older age, but that she has more time to organise herself. On another occasion I observed a man who was sitting in the waiting area, he was reading a magazine and didn't have a name badge on as patients usually did. He looked to be in his 70s. I asked him if he would like a cup of tea as there didn't appear to be any volunteers around, he thankfully replied

"oh yes if you don't mind but I'm not a patient I'm a driver I'm just waiting for my patient". *(Taken from field notes 30th November 2017)*

I said that was ok and made him a cup of tea. I gave him his drink and sat with him, I asked him if he was a taxi driver, he told me that he was a voluntary driver for a community cars scheme. He laughed as he said even though he could easily be one of the patients at the Day Hospital he took up volunteering when he retired and stated;

“If you don’t do anything then your brain starts to rot from the inside”

(Taken from field notes 30th November 2017)

He went on to tell me that he worked in a high-pressured job all his life and that he used to watch people retire and sit at home doing nothing and then they would have a heart attack and die within three months. He didn’t want that to happen to him, so he feels that it’s important to do things to keep you busy as you get older. He said

“Mentally you don’t feel different, but things wear out, and it limits the things you can do”. (Taken from field notes 30th November 2017)

He continued saying that he felt really sorry for ‘*his patients’* as it must be awful losing the ability to drive and have the freedom. He said that freedom was a really important thing to him, being able to just step out of the house and get into the car enables that freedom. As he talked, he became more animated and seemed more enthusiastic about telling me all the things he does to keep himself busy. He closed his magazine and turned his chair more to my direction as he described how both him and his wife were heavily involved in charitable volunteering, he felt that it was good that they did things together but also “*important that we are not joined at the hip*”. He was part of three choirs and a part-time choral society member but didn’t always sing, this was something he took up as he retired as he liked the group of people and found them friendly. He said at times they go to nursing homes and “*sing for the old people*”, he seems to laugh to himself and make a comment about him being an old person afterwards but clearly made some sort of definition between himself and “*the old people*”.

After a while a man came to the table with one of the physios, she is a senior physio who has worked for the Day Hospital for a long time and I would estimate her to be in her 50s. The man at the table I was talking to said “*oh here’s my patient now*”. The patient sat down, and the physio said, just wait there a minute I’ll be back with your new stick. The driver indicated in my direction and said; “*this girl is interviewing me about my volunteering*”.

These interactions demonstrated the importance of driving for both the female patient and the community driver of a similar age. They describe driving as freedom giving, and this freedom is considered to differentiate them from others in their peer group. The driver uses dependency and inactivity as a marker of old age rather than age itself, and he uses his activities to differentiate himself from the patients that attend the Day Hospital. This concept of distancing one's self from others who you consider to be less able has been highlighted in previous literature (Grenier 2006; Warmoth et al. 2016) as discussed in the literature review. Of note for me was his keenness to portray himself to me and the patient in terms of his activity and ability.

Loss of functionality and subsequent independence was discussed extensively throughout the patient focus group, in particular the group discussed a number of situations where they felt they had lost the ability to do things that they felt they "*should be able to do*". Both in the observational phase and the focus groups it became evident that people experience a dichotomy between the things they want to do and the things they are physically able to do. For example, in the patient focus group the following discussion took place:

Robert: it's my arms as well I go out so (shakes head), I mean to go out there and do things I just can't

Anne: you can plan all sorts of things in your mind

Robert: that's right I'm sitting there

Anne: you've almost done them until you've tried to do them

Robert: that's right and then when I do do something I've got to go and sit down for half an hour before I can do another bit, that sort of thing because I'm frightened my legs are going to collapse

(PFG lines 169-176)

This dialogue highlights the loss of control people feel over their physical functionality even though their intention is clear and clearly thought out. Brenda describes this as "*the brain being different to the body*" and suggests that this dichotomy is a way of self-protection from getting older.

Brenda: it's also the brain being different to the body isn't it, you know in your mind

Adam: yeah

Brenda: you're still 21 and you can do all these things, and you go to do them and realise actually now I'm getting older, but my brain isn't allowing it to happen. It's almost a protection isn't it; don't want to think about getting older keep yourself thinking young. *(PFG lines 187-192)*

Brenda is suggesting that if you think 'young' you might be able to stop yourself getting older, this somewhat reiterates the points made in the previous discussion with the driver who differentiated himself not by age but by ability. This concept was also highlighted in the observational phase as some people chose to disassociate themselves with friends of the same age. During a conversation between two patients one woman commented:

"I don't have friends left that are my age. I don't want to be with old people. A friend of mine said she couldn't do something, she said I'm 73 you know. I said hang on I'm 93 and I can do it. No, I couldn't think of anything worse".

(Taken from field notes 15th December 2017)

During another conversation between a volunteer and a patient the patient said that she doesn't want to spend time with people her age, the ones she knows are all depressing and don't do anything, she wants to laugh but they just moan (paraphrased).

Loss of functionality and anticipated losses appear to play a significant role in the lives of the patients treated in the unit. At the start of their journey through the Day Hospital, older people appeared to carry many losses with them. There is an ongoing fear regarding the potential of anticipated losses that are believed to further lessen the person's control and independence. These fears can lead to altered behaviour such as: self-imposed restrictions on contact with health professionals to avoid highlighting needs, and presentation of self to others as independent, which may impact upon them accessing help in risky situations. Functional losses are frustrating particularly as patients felt there were things they 'should' be able to do, and suggested separations between their thought processes and their physicality. Splits between their changing bodies and their psyche impacted upon their identities, their bodies were sometimes unreliable and separation between the precariousness and unpredictability of them against their mind sets appeared to annoy people. Similar experiences of splits between self and body have been highlighted in other people who have experienced events such as a stroke. The body loses its invisibility (Ellis-Hill et al. 2000; Westerhof 2012; Nicholson 2017). Some appeared to have developed strategies to try and overcome these feelings such as distancing themselves from others that they consider to be frailer than themselves, yet this often reinforced felt isolation. The losses felt were referred to in terms of functionality rather than age, older people did not appear to consider their age to be the most influential factor in their functionality, but rather their life losses.

7.4 Identity - Re-balancing and negotiating physical risk vs social risk of being ‘old’.

As described, for most of the older people functional ability was used as a way of defining themselves. Older people described and presented themselves to staff through their functional abilities and often appeared to feel that others attempted to restrict and limit their actions. Although older people alluded to the fact that they have minimal control over their own health and functionality at times, there was a sense that people actively attempted to retain their independence and control the level of intervention they deem necessary. For some people this was revealed as a reluctance to engage in intervention and/or denial that there were problems. For example, during an observation in the waiting area I observed two women, one younger than the other, who sat down at the table I was on. Both smiled and nodded in acknowledgement as they sat down. The older woman stood out particularly as she wore a beautifully coordinated outfit, her hair curled and set, and her jewellery picked out the key colours of her outfit. As she sat down she fell back slightly in her seat and the younger woman tried to catch her, she turned to her and brushed her away and said to “*stop fussing*”. The younger woman looked a little annoyed and said, “*mum I’m just trying to help*”. They sat down and each picked up a magazine from the table. I felt a little tension between the two but sensed that this may be a good session to observe. I introduced myself and they consented to me coming into their assessment.

The older woman was coming in for her initial assessment, the younger woman was her daughter. As the conversation progressed you could see that the patient appeared frustrated with the daughter, she made inferences that the daughter was ‘making a fuss’. There were jokes made by the patient telling the nurse not to listen to her daughter as she lies about her and that there is nothing wrong other than her daughter worrying about her all the time. The overriding sense of the meeting was that the patient felt frustrated by the falls she had been experiencing, she felt equally frustrated that she perceived her daughter to be restricting her life. The daughter appeared to be genuinely caring, but perhaps somewhat annoyed that her view on things was dismissed by her mum. During the assessment the daughter sat behind her mum and would make facial gestures in response to some of the questions that the nurse was asking her mum if she felt she disagreed with the answer. For example, the nurse was asking do you have any near miss falls or stumbles, the patients said no but the daughter was nodding her head behind her and mouthed “she does a lot”. There was a sense that the mum is struggling to come to terms with some of the things that are happening to her and is in some denial of them.

Although there was no indication that the daughter was restricting her mother’s independence there was a strong sense that the mother felt the daughter’s fears were unnecessary. During the patient focus group this kind of experience was also discussed in terms of restrictions imposed by spouses on their partners. Patients discussed how their partners would impose physical restrictions on going out or doing certain activities such as lifting or carrying

Adam: well that’s what my wife kept telling me you mustn’t climb up that ladder and do the hedges anymore leave it

Laughter

James: yeah know I know that feeling

Adam: but now the wife has gone and I’m on my own there’s no one to tell me not to climb up the ladder *(PFG lines 290-295)*

Although discussed with an element of humour and acceptance of their partners' views they continue to try and do these activities, when possible, even though it may cause difficulties in their relationships and indeed may put them at risk of physical harm.

Robert: I always think when my wife pops out, when she's gone out I'll try and do that. 'Course then I get told off when she gets back, you shouldn't have done that.

(PFG line 304)

This type of behaviour also extended to not calling for help unless there appeared to be no other option due to fear of others involvement, even if they have injured themselves. This was evident whilst the patients were discussing the use of home call bell systems

Anne: I should wear mine, and yet I don't, when I fell over I wouldn't use it, I thought no I'm not going to use it , I don't want to be taken to hospital I'll see if I can manage without doing that, then I had to wait three weeks to see a doctor and after I found out what the fall had done to me, I had trapped a vertebrae in my spine, so I should of, I should have done it, I've been told so many times, I should have pressed it.

(PFG line 330)

Anne recognised the impact of not getting help following her fall, yet she did not want to use her call bell due to fear of her being admitted to hospital. Kristensson et al. (2010) identified that many older people with frailty experience loss of power and control in relation to hospital admissions which impacts upon their wellbeing. Andreasen et al. (2015) also suggest that intervention from others can inhibit rehabilitation of the older person suggesting that 'the system' either didn't provide adequate support or that the support provided didn't meet the expressed needs.

Hospital admission has many daily life consequences for self and others, during the patient focus group the importance of routine was highlighted on several occasions. During a hospital admission this routine 'balanced' life would become unbalanced, the fear of which appeared to impact upon patients' calls for help.

Brenda found herself in a similar situation to Anne's

Brenda: if I had it I don't think I would have called the ambulance because I thought then they'll cart me off to hospital, what do I do with the dog, problem with the wheelchair, then if they discharge you, you have to make your own way home. Where I live there are no buses, getting an adapted taxi, so I thought oh I'll be fine. But it turns out I'd actually fractured a vertebrae which in hindsight I should have gone to hospital with but, so I think sometimes we have to have these things happen to make that wakeup call *(PFG line 335)*

Brenda's reference to caring for her dog and potentially having to navigate her way home from hospital suggests the complex chains of events that are considered in relations to a person's actions. The hospital system would not necessarily recognise or provide support for these life consequences.

Both Brenda and Anne also highlighted anxieties regarding needing personal care

Brenda: it's also, I find I have to have carers in sometimes, but I'm a fairly sort of modest person and having to actually have someone shower you and dry you

Catherine: oh absolutely

Brenda: to me that's quite invasive and I still can't get my head round allowing people to help with that because

Anne: that's right that's what I find as well

Catherine: yes *(PFG line 460-466)*

Some older people described that needing assistance with personal care was difficult to accept. Frequently during the observation phase people in the waiting area would pass comment about others who needed help with feeding or assistance to go to the toilet; the comments were often linked with pity and indicated an aversion to such help. During the patient focus group Brenda describes personal care as 'invasive', a feeling shared at least by the other women within the group. During the observation phase I also witnessed patients developing systems in order to avoid the need for carers for personal care such as washing their top half in the morning and the bottom half in the evening.

They felt that this system meant that they were able to have a full wash each day whilst managing their fatigue. At times there appeared to be frustration within the staff that patients might refuse support from carers. It did feel that there was a perception that older people should accept care if it is deemed necessary by the therapist, and perhaps little understanding about how this would appear to be ‘risky’ for the person in terms of their identity.

Actions that are considered practically risky, such as not using their call bell, may be taken to avoid the need for intervention by others so that people feel that they are retaining a level of control in a world where they see that things are ‘just happening to them’. This type of behaviour was also seen in Ballinger and Payne’s (2002) study looking at construction of risk of falling in a Day Hospital. Ballinger and Payne (2002) found that whilst the staff were focused on physical patient risk reduction, patients themselves were more concerned about the social risk to their identities and experienced interactions in which they felt stereotyped and infantilised. Other studies have also found that some older people avoid social interactions due to fears that their preferred and self-perceived identities would be threatened, this mainly focused around their independence and youthfulness (Goll et al. 2015).

It was also clear that restrictions were not only considered to be imposed by healthcare workers. During the relative focus group members talked about the concept of restricting their loved one due to fear of something happening to them. These restrictive practices were brought up several times throughout the conversation and it was referred to as “*having to continually risk assess”* the person. The feeling of having to continually risk assess, whether justified or not, appeared to place added strain on the relatives and at times, on the relationship between the two people. Many of the relatives spoke about working in isolation and not always knowing what was best to do for their loved one. These feelings reflect those described by other care givers in the wider literature where consideration of their relatives’ engagement in everyday activities were time consuming and demanding (Chung et al. 2017; Hand et al. 2019; Hawkley et al. 2020).

Pete spoke about how he felt he had to think twice about everything his wife does

Pete: I think the thing that was pointed out to me was that I'm doing a risk assessment of her in everything she does

Cathy, Betty and Sam nod in agreement, Sean: yeah

Pete: which is you know I haven't had to do in the same way as I'm doing now like carrying hot water or getting it on the stove, I think twice she has walked away and left something on the stove and it bubbled and burnt away, but that's just a recent thing, I'm now aware of it so I better keep an eye on that sort of thing it's, and also, in parky (Parkinson's) folks tend to fall backwards. I'm trying to get her to stand close to something or have something behind her, so if she goes backwards, there's no stopping her if she fell over in the bathroom, I just walked out the bathroom and she fell over, had to go to hospital and have an x-ray. And it's as I say risk assessed.

(RFG lines 410-420)

Assessing these risks also led to relatives considering their own mortality and they started to impose restrictive practices on themselves in order to minimise any risk of leaving their loved one in a position where they could no longer care for them. This showed the impact of frailty not only on the patient but also their loved ones.

Pete: I had my aorta replaced in January last year, so yes I got caught out with that one, so it was an emergency situation and I nearly left her behind, and no plans for that really, yeah so, that's affected me personally and we had a car accident 5 years ago and nearly got wiped out then so we are not doing too well.

Cathy: I think that yes your own health worries you much more, you are suddenly aware you are the person who is looking after the individual and I worry about if anything happens to me how my husband is going to cope. I've gone through my mother, you know, and it's a question of when's it going to stop, it's an additional pressure and you're constantly aware that you're going to have to reassess things and you can't discuss it with the other person because they are relying too much on you .

(RFG lines 430-439)

There was a sense of isolation in the group, that the relatives felt a constant pressure to be aware of eventualities and to have planned accordingly. This created worry as they recognised that many of the health crises they were experiencing came as a shock to them and were unexpected at the time. Many have had to change roles within their relationships, a balancing act had been created for the majority of the relatives, (who themselves were older in age), between managing the risk of the activities of their loved ones, and themselves whilst appearing ‘fit’ enough to continue to care for them. They suggest a need to maintain equilibrium in both their and their loved one’s lives.

Overall, the older people tried to maintain balance in their lives by implementing routines and negotiating risks in order to portray independence. Restrictions were often imposed by others, underpinned by a perceived risk, but these risks were often dismissed by the patient. Symptoms of frailty impacted upon the balance of daily life; some activities were deemed ‘riskier’ as recovery was considered to take longer with the added complexities of frailty.

7.5 Identity - Lack of social identity, leading to loneliness (world closes)

Both patients and relatives made references to perceived changes to their roles in their personal lives, many of the relatives discussed how they had adopted new roles that their loved one had previously done; for example in the relative focus group Sam comments on her new responsibilities since her husband’s stroke

Sam: yes yes, because I don’t care for myself as an old fashioned wife but my husband was the one that paid the bills and did everything and was the main driver

(RFG line 24)

It was clear from both the observations and the focus groups that many people, particularly relatives, experienced changes in their life roles with their partners. Some of the male partners found that they took a while coming to terms with these changes but also acknowledged that it was difficult for their wives to accept the changes.

Sean: so, it's coming to terms with realising erm, like you (pointing at Cathy), my wife did all the admin, all the banking and I was just pleased that it said black in the account at the end of each month. Erm, so I had to come to terms with learning that. I've always enjoyed cooking, but as a leisure rather than a necessity, erm, and I will never, ever do things as quickly and as fast and as efficiently as my wife used to do them, and that's something that she is having to come to terms with as well, so the benefits of this weekly session, I know isn't there for a limited period of time but, erm, I don't believe any one will appreciate apart from us carers how import the programme is in rehabilitation or just maintaining a quality of life perspective for our partners.

Cathy: it's a big role change often isn't it *(RFG lines 119-129)*

Pete talks about how he had to learn things he didn't expect to have to learn, reiterating the idea that many of these life changes come as a shock and are not considered as part of the ageing process and something that should be prepared for. This perhaps suggests that people do not see older age as a time to learn new things, which may have important impacts upon how people relate to the new things they must learn in order to reduce their frailty.

Changes in social identity, (a person's sense of who they are based on groups that they position themselves in their world (Abrams 2001)), became more evident in patients who were bereaved. For older people who were bereaved their sense of social identity appeared much cloudier than others. For them it was not just that they had to adapt to new life roles but also that the sense of who they are in relation to others had changed and become more dynamic and uncertain.

Whilst observing I struck up a conversation with a man in the waiting area who appeared to be alone, he was quiet initially, but I offered him a hot drink and he appeared to relax more. He told me that his wife had died and that he had been alone for a while now. He said

"I'm in a house, it's quite a big one, and well I think so anyway. I can't remember how long I've been on my own now, it's been a few years, but you forget (he laughs). I'm ok with my own company but you get a bit lonely you know. They want me to go down to Wales for a holiday, but I have to get the bus now as I'm not safe driving. I had to give it up. After 58 years I gave it up". *(Taken from field notes 14th May 2018)*

He acknowledges that he feels lonely even though he is ok with his own company. Like those previously he talks about having to give up driving and reiterates giving it up after 58 years which signifies such a loss. The man was very quiet, he didn’t look up to engage with passing staff or look for attention, however when I asked him if he was with anyone he seemed to quickly open up about the death of his wife. When he was talking there was a great sense of sadness but also loneliness, it felt as though he was almost justifying why he was there alone. He reiterated that he felt lost without her several times during the conversation. The death of his wife had altered his social role, he still felt like a husband but no longer had a wife to share that with, to care for or provide for. Although he said he accepted his own company he describes feeling lonely and although other family members appeared to try and support him from afar, there was a great sense that he felt their suggestions were things that they wanted to happen rather than what he wanted.

Bereavement is a loss that had been experienced by many using the Day Hospital, mostly spousal loss but some older people had also lost their adult children. During the observations a man caught my eye in the waiting area. The first thing I noticed about him was the amount of gold jewellery he wore, several rings on each finger and a chunky gold chain. He visually looked different from the other patients coming into the day unit. He acknowledged people as he walked through the waiting area with a nod, but mainly kept his head down. He looked sad but I couldn’t explain why specifically. He was alone and walked with a wheeled rollator frame. Looking around the room I notice that everyone else was with someone, perhaps therefore he was particularly noticeable.

I went and sat near to him; he looked up and smiled but didn’t start a conversation. I noticed a strong smell of cigarettes, I realised I hadn’t smelt cigarettes on anyone at the Day Hospital since I had been there. He seemed slightly nervous, fidgety and moving around in his seat and didn’t make eye contact with people, he wasn’t reading a magazine or paper just looking downwards. Visually he appeared personally neglected, his nails and clothes were dirty, and his hair was long and unkempt.

I made him a drink and sat next to him whilst he drank it, he asked if I worked there. I explained that I was a researcher and showed him the leaflet about the project that was on the table. He told me that he had been coming for a few weeks to get help. I explained that I was trying to understand people’s experiences and how they got help, he agreed that I could come into his treatment session with him. Whilst waiting we sat and had a general conversation about the weather and how he had got to the Day Hospital. He told me that he had a friend that brought him in and that he felt lucky to have friends. I asked if he had a lot of friends, but he then said that they weren’t really friends but neighbours. We sat in silence for a while; therapists and nurses came out of the office and called out names of patients they were looking for. He looked up each time a name was called.

There wasn’t a great deal of chatter in the waiting area couples sat together and had whispered conversations between each other. The man’s name was called by a nurse, he put his hand up and she came over to great him, she obviously knew him from previous weeks. She called him by his first name as they walked towards the treatments rooms he began to smile as they chatted, the nurse asked how he had been, and I was quite surprised to hear how animated he became when talking to her. They seemed to have a good rapport he said he felt very lonely this week, he continued to talk as he sat down, and he became tearful as he explained how he missed his wife who had died two years prior.

I thought this was why perhaps he seemed slightly disconnected from others around him, because he was bereaved. The nervousness that he displayed may have been related to the loss he was evidently feeling. It seems reasonable to assume that this grief is harder to share when you do not know their story, it is fairly easy to laugh with someone over an innocuous joke in a waiting room but sharing a painful experience is much harder. The man was much more relaxed with the nurse than with others in the waiting room, they seemed to have an affinity; I sensed that the nurse understood the patient and his feelings well.

He explained that the occupational therapist, on a previous appointment had asked him “*his deepest thoughts*” which triggered a painful response of loss. He said he didn’t want to forget his wife. There was a sense that he felt pressure and expectation from others that he needed to move on.

After the meeting I reflected with the nurse, she said that it had been difficult to engage with him initially as he didn’t want any bereavement counselling, but she felt that the loss was really “*holding him back*”. I thought then that although the nurse’s statement seemed well intended, the phrase “*holding him back*” did perhaps support the patient’s idea that there is an expectation for him to move forward.

Even for those who appeared to have relatively more active social lives, loneliness appeared as a thread in the conversation. People recognised that the dynamics of their social groups were changing, that their friendship groups were getting lesser as friends may become less able to meet up, not able to drive or indeed die, their social world became smaller (Cornwell et al. 2008; Goll et al. 2015; Hagan et al. 2020).

The importance of social engagement is significantly demonstrated and acknowledged within the volunteers at the Day Hospital. During the observational phase I witnessed the strength of relationships that the volunteers made not only with the patients but also amongst themselves. During the focus groups it became apparent that the volunteers had been serving the Day Hospital for between 10 and 20 years and that the volunteers play an important role in the Day Hospital and it is quite noticeable if they are not there.

The small kitchen off the waiting area is for the benefit of the patient’s predominantly. Staff can make tea and coffee in there but are not allowed to use the fridge for storage of lunches etc. The kitchen feels like the volunteers’ domain, whenever I went in there they were bustling around with cups and saucers and refilling coffee, I always felt a bit in their way. There were signs up for the volunteers to read from the staff regarding social activities and inviting them along. The volunteers tend to work in twos and are all women apart from one man John. John is very chatty with a dry sense of humour; he does a lot of talking. Peggy the other volunteer who works alongside him appears less obtrusive and is constantly doing things in the kitchen. She tells John what to do and occasionally seems a bit frustrated that he is often talking more than he is working. John stands against the windowsill in the kitchen while he talks to me whilst Peggy is doing something in the cupboards behind me. I know Peggy is listening as she says things in relation to the conversation now and then.

John said to me “I see you’re having a bad hair day today” and laughed, Peggy told me to ignore John as he is a joker. John explained how he felt he needed to cheer up the patients but also that volunteering kept him healthy and occupied. He spoke about how he gets bored at home and likes to be around people. He said that he lived alone but I didn’t ask him if he was divorced or widowed as new patients began to arrive. John seems to like to sit and chat with the patients more than Peggy did, she always seemed to be on the go cleaning, wiping, putting things away or getting them out.

Like the volunteer driver previously discussed, the Day Hospital volunteers distinguish themselves from the patients by their abilities. One key feature that they attribute to themselves as a group was their ability to support patients socially and reduce loneliness and isolation. They also recognised that volunteering was helping them to remain socialised and reduce the possibility of them becoming isolated. For example, during the volunteer focus group the members discuss the fact that they have stayed volunteering at the Day Hospital for a long time

Bernie: well it’s what makes you enjoy coming really

Sarah: well I suppose that’s one of the reasons why we’ve come for so long, so many years, because we’ve enjoyed it

Gemma: yeah we wouldn’t have stuck the test of time if we didn’t enjoy it would we

Everyone says no

Sarah: I think they’ll have to take all of us out kicking and screaming

(VFG: line 490 – 484)

The volunteers gain enjoyment and purpose in their role, saying that they will have to be taken out kicking and screaming suggesting a real sense of belonging and not wanting to leave. The volunteers also discuss changes in their thought patterns as they age and recognise reductions of their own social circles

Sarah: you know as you get older your whole psyche changes doesn't it, I think you think differently

Amy: yes, you want different things; you don't necessarily want to do what you did

Sarah: if you think of how you were even 20 years ago, I think you know you are different. At least I am

Bernie: well you can't do (inaudible), you think you can, but you can't

Sarah: yeah but I think also differently, you know you may have been more outgoing, especially as you said people you know start dying off so already your social group starts shrinking

Bernie: yeah so you've got to find some new

Sarah: so, you could you know slowly start coming back, back before you realise you're stuck

Gemma: that's when you've got to be careful you know and just do something else

Sarah: yeah yeah *(VFG: lines 567 – 579)*

This conversation highlights the belief that both your physical and mental state change over time and that you can become 'stuck' if you don't find things to keep you occupied and socially engaged. Many of the volunteers have been widowed and experienced similar loss to those attending the Day Hospital as patients and recognise that their roles give them focus and opportunity to speak with people.

Bernie: well when you're widowed it's another day to focus on

Amy: when you're on your own it's nice to get out and about and chat to people and its ideal here. *(VFG: line 113 – 114)*

Although volunteers differentiate themselves from the patients this data suggests that they are experiencing some of the same types of losses and feelings that they have. It is evident that there is a line of thought that keeping active will stave off old age, the sense of avoidance of aging and social isolation in some of the volunteers is so strong that they are planning for the time that this may happen due to physical deterioration. During the volunteer focus group, they discussed their concept of what happens when you get old

Moderator: do you see similarities or differences between yourselves and the patients then?

Sarah: yes, I see myself there eventually, eventually I mean most of us will, and unfortunately it's the old legs that go first. I mean in our kind of age group we are much more physical, we keep going, I mean even when I think back to my parents, to my mother I think you could say even in their sixties you would say she was an old woman.

Bernie: they were old then weren't they

Gemma: late 50s or 60s they were very old.

Sarah: I think every generation we've got younger in our outlook and of course we have kept more active which is a big thing. And the more active you are I think it's better for you, but then it's all in your genes as well if you are just someone who enjoys sitting down reading everyday

Gemma: you don't want to do anything

Sarah: you don't want to do anything that's just it

Gemma: you sort of pull your world back in don't you

Sarah: exactly and this is it, you see, this is what's happening, a lot of people don't like to, they like to be independent, but they're independent, they're sitting at home they're getting a carer that comes in, someone that comes in and throws some food at them, another carer comes to see they are ok, so that's all together per day they may have somebody that comes in for an hour and the rest of those hours they are sitting on their own.

Vicky: I'm not even sure it's an hour.

Bernie: half the time it isn't is it

Sarah: so I think, but this is my own personal thing, I won't do that, I've already said I'm going in to some kind of home where there's people, but some people don't like that.
(VFG: line 191- 213)

There is a sense from the conversation above that the age landscape has changed, the volunteers see themselves as 'younger' than previous generations and attribute this to activity.

7.6 Identity – Active control vs inevitable endings.

Although the volunteers appear to see their levels of activity as something they govern and have control over, there is also an underlying contradiction that they will find themselves in the same situation as the patients in the Day Hospital, as 'this is something that happens to people eventually'. The concept regarding their legs giving up is an idea that appears to be shared by others throughout the observational phase. This suggests that older people are living in a world where they are trying to maintain their independence or at least appearance of independence to others as well as navigating their social roles. Yet these roles are dynamic due to bereavement or their friendship groups changing, but with an underlying sense that much of what might happen to them is down to luck.

Many of the patients and their relatives discussed their health in terms of luck/chance. For those who felt they were relatively healthy they would refer to themselves as lucky or compare themselves to others in the room saying things like "*at least I'm lucky I don't need one of those*" (referring to the wheelchair). During the observational phase one woman discussed her sister who had cancer; she was telling me that she felt guilty as her sister had seemingly had a much healthier lifestyle in her eyes. She seemed self-aware, she recognised she had participated in activities that were generally deemed unhealthy such as smoking, drinking and eating out a lot. She said she felt sad for her sister but that she also felt 'lucky' that she was doing well for her age.

The concept that healthy ageing is due to luck was a thread that I identified from a number of observations and conversations, in terms of preventative interventions and to some extent therapeutic interventions, this concept, if widely held as it appears, may have significant impact on motivation for the older people involved. If the belief is that you are just lucky if you are in good health, then there is little motivation for the person to take many preventative measures. Self-efficacy, the belief we have an ability to successfully achieve (Bandura 2010), could be severely challenged when a thought system is developed where health is based mainly on luck/chance. This in turn may impact on their self-esteem (feelings of worth) and motivation (or desire) to engage in rehabilitation and achieve the agreed goals.

7.7 Identity – Fearing loss of agency

The themes I have identified in this section all include elements of fear. Older people have demonstrated fear regarding loss of functionality, increasing dependence or the threat of, lack of social interaction and isolation and fears regarding changes in their role and social identities. Fear in differing forms played a role in the lives of older people.

During the observational phase, many people would enter the unit looking fearful of what may happen. I didn’t realise the extent of this fear until I spoke to some of the volunteers who appeared to deal with it daily. They describe having to provide comfort to many patients who arrive in tears, anxious about coming to the Hospital or what may happen. There remains a large body of literature highlighting ageism within healthcare practices supporting the concept that older people may not access healthcare services due to fears regarding loss of agency about their future (Pritchard-Jones 2017; Wilson et al. 2017; Wyman et al. 2018). This was alluded to during the observational phase by one of the patients talking about his wife

Pt3: I never knew anything like this existed really until I came here, my wife at home she should be coming here not me. She needs to go and see the doctor, but she won’t go. She has fallen 2 or 3 times.

I ask why she won’t go.

Pt3: I don’t know (shrugs) that’s just her isn’t it.

(Taken from fieldnotes 23rd January 2018)

This was also demonstrated previously where patients were avoiding the intervention of health professionals following a fall.

Patients were not only fearful of their future, many had immediate fears regarding recurring illness. If we think about frailty in terms of reduced capacity to recover, then it is easier to understand why many patients and their relatives may be fearful of another health event when they have not fully recovered from the first. James talks about fearing another stroke during the patient focus group.

James: see, I had a stroke. And one of the nurses sat down with me and explained what had happened, the thing is you're afraid it's going to happen again and you're, you're not actually waiting for it but you are afraid it's going to happen again, err, she sat down and explained erm where the clot had been, and she said it's not there now, she said, that has gone because the amount of drugs we are giving you she said would disperse that, so she said you haven't really got any fear over that, and she said why you're a bit slow is because you'll always have a blockage where you've had the, well not actually a blockage she called it a pothole in the road and I thought that was brilliant, (PFG lines 143-150)

He talks about his fear and that the explanation about his treatment from the nurse helped to allay this to an extent.

James: yeah. But no when she sat down and explained that away it made you feel more comfortable (PFG lines 155-156)

Many of the older people felt that they had to demonstrate their capabilities to maintain independence and avert intervention. They appear to try and diminish the concerns of others whilst simultaneously fearing something may just "happen to them". Fear of falling was discussed several times during the observational phase. I think this was something I expected to see, as many of the patients were there for rehabilitation following a fall. Fear of falling had several complex elements, there was a general belief system that if you fell and sustained a major injury such as a hip fracture then you were sure to deteriorate. During one observation a few patients were discussing dog walking

Pt1: (points to physio assistant walking past) that are the physio that takes the class, she is so good. When you get older things just happen, but it works it strengthens your legs (referring to the exercise)

Pt3: unfortunately, on the way here last week I got a speeding ticket. I've got to pay £100. I've seen a lot of changes over the years they have spent a lot of money haven't they

I nod in agreement.

Pt1: getting a dog might be good for you. My other neighbour had a dog she was 80. It was so excitable this dog.

Pt2: no, I would be scared it would pull me over and I would break something that would be the worst. If you break your hip it's all downhill from there.

(Taken from fieldnotes 23rd January 2018)

Several older people mentioned this type of thought process over the months and it became clear that the fear was not of the fall itself but the potential consequences and subsequent loss of independence. This was a belief held not just by the patients and relatives, but also by the volunteers

Amy: well most older people have problems with their legs

Sarah: peoples legs, seems to have problems with the legs, first its balance and then of course as soon as they have a first fall their confidence goes.

Gemma: that's right and that's the hardest thing to get back is your confidence

Sarah: because a lot of people have gone on a bus somewhere even into town, but as soon as you fall that's it, so you are terrified of going out and it goes very quickly where your boundaries, your frontier is your front door. Very quick, and unfortunately they don't ask for any help, you know going into day centres, there is so much out there that you can do.

(VFG lines 228-234)

The fear seemed to increase for those that lived alone. Generally, people said that they were more scared when they were on their own

The nurse asked her if she sleeps ok, she said she sleeps well but she does worry a bit about being on her own at home and falling over.

(Taken from fieldnotes 8th May 2018)

Most patients in the focus group lived with a partner, they discussed their fears about being without their partners and recognised their reliance upon them. This dialogue followed a discussion about the importance of individual routines and how when they were acutely ill their reliance on others meant that their routine life had been disrupted and they felt they had little control.

Brenda: I think I worry about being alone, although I'm fairly independent I rely quite a bit on my husband and I think if I was on my own, would I be able to still live where I am, how would I cope, with things I can't do.

(PFG lines 423-425)

James agreed with Brenda, and Henry mentioned his fear of being "put in a home". Much of this fear seemed based on lack of control of their situation and not knowing what might happen to them due to their need for assistance.

When asked about fears, the volunteers experienced similar fears for their future; they talked about losses in friendship groups that made them consider their own vulnerabilities.

Moderator: so, you experience these sorts of fears then that perhaps other people

Everyone agrees yes

Gemma: oh yes I think more as you get older, don't you think?

Amy: yes, if you're on your own, very much so, especially at night, I really feel (takes a deep breath in for effect) you know anxious.

Gemma: I think the more your friends around you, because I suppose at our age your friends are dying you know, and the more of your friends that pass away it makes you think of your own vulnerability

Amy: that's true

Bernie: you think we're getting to the top of the tree

Yes laughter

Vicky: the group is diminishing as you know it, my turn next

Laughs

Sarah; oh yes it's all going to come to us isn't it eventually

(VFG lines 284-297)

It was the volunteers who offered the most information about what they believed happened to older people and recalled several anecdotal tales of friends and relatives who had needed care, some had chosen how they wanted to be cared for based upon others' experiences.

Sarah: I've already said I'm going into some kind of home where there's people, but some people don't like that.

Gemma: somewhere where there's activities, sitting there all around the room, I couldn't do that no

Sarah: but then there again if you go into a really good care home. You know it costs £1500 a week. It's a fantastic home; they do a lot of things

Amy: where's that?

Sarah explains which home

Sarah: its fabulous people are doing everything

Amy: and if you want to join in you can

Sarah: exactly but it costs an arm and a leg, well more they will have to sell the house, well she's 92 now, but it's a lot of money and she could last another 5 years at least by which time the moneys run out, so this is the thing with us we are all living a bit longer .

(VFG lines 205-224)

They acknowledged that most people wanted to remain independent by being at home, but their concept of home care involved someone coming in to "throw some food at them" and check on them infrequently. Sarah felt quite strongly that she wanted to be in a home to be able to socialise but also voiced concerns over the implications of living longer in residential care.

7.8 Section summary

Overall fear appeared to be a major challenge to sense of self and a contributing factor in many aspects of the lives of older people which impacted upon the actions they took and the decisions they made. Belief systems regarding potential consequences of decisions are strong amongst older people with and without frailty. Social roles for both patients and their relatives change over time. People must adapt their lives to fit with what feels to be an unpredictable and dynamic state of frailty, the constraints of which are often imposed upon them by others due to their frailty status and their perceived vulnerability. Bereavement had a significant impact on many of the people using the service, changes in social roles either through illness or bereavement can lead people to feel lost and isolated as they see their social circles, friendship groups and abilities diminish. Their world becomes smaller at a time when they are likely to need more. Remaining socially active was a coveted activity; throughout all groups it was believed that remaining active was important to stop deterioration. This was particularly clear in the volunteers who felt that this was one of the main reasons they continued their roles.

Chapter 8 Findings Section 2 – Fostering a hospitable environment

“The very first requirement in a hospital is that it should do the sick no harm.”

(Nightingale 1863, pg.iii)

In the previous chapter I outlined how patients and their relatives entered the Day Hospital with several losses both physical and psychological and how they negotiated these in the context of their personal and wider social identities. This next chapter depicts the processes which occur within the Day Hospital that help to construct a positive path for older people with frailty and how these processes impact upon engagement in services. I found that the Day Hospital provides a place of safety and acceptance for people to manage their life changes and fears in a healing and nurturing environment. Patients, relatives, staff and volunteers developed relationships which allowed them to recognise where they are currently and feel emboldened to move forward.

8.1 Welcoming the stranger – come in we’re expecting you

One of the first things you notice when entering the Day Hospital is space. The external walls of the entrance porch are made entirely from glass floor to ceiling, with automatic doors creating an effortless flow through to the main reception lobby, as I entered I found myself gliding through to the reception area with no physical effort. The vast expanse of glass in the porch lobby allows a connection to remain with the outside greenery which is well maintained. Although it is not filled with plush vegetation or flowing mountain springs as some may consider a traditional therapeutic landscape to be (Gesler 1992), there is a sense that the greenery is well maintained and cared for, it is clean, free of litter and for those patients who are mainly housebound may feel like a pleasant space. In western society there is a strong ideology that health can be improved by being outside (Gladwell et al. 2013), this seems particularly strong in the older generation many of whom had to spend hours of a day in factories or in poor working conditions, I certainly recall my grandparents often using phrases such as “let’s get outside for some fresh air” or going to the sea for some “sea air” when they were feeling unwell. I will touch upon the concept of therapeutic spaces later in these findings, but certainly there is a sense that this openness between the entrance and the outside creates a feeling of relaxation.

The reception itself is spacious, the corridor wide enough for three people to pass each other with minimal disruption. The reception desk is set in the corner facing the door and opens behind to a small but open plan administrative office where generally one or two staff work on computers. The first thing you notice about the receptionist is her wide smile, she greats people warmly with a loud but cheerful tone. There were often small queues of people waiting at the reception, although it never felt crowded due to the space. The receptionist uses terms of endearment to both staff and patients as they enter or simply pass by the counter. The countertop is low level, and as you look into the office there is a feeling of openness about the environment. On the counter there is usually a list of patients who are due to arrive that day, patients move slowly towards the desk often with Zimmer frames or sticks, she waits patiently smiling and says things like “hello darling” or comments on the weather. Many have papers in their hand which they try to pass to her as the reach the counter, she glances briefly at the paper but appears to have memorised the names on her list as such says “oh yes Mrs Smith we are expecting you”, she rarely refers to her sheet and if she does it is always after the patent has been welcomed in to the unit.

As an observer this interaction creates the sense that the patient is expected, they are in the right place at the right time. Feeling expected has emerged as an important element for patients and relatives coming to the Day Hospital, they have often experienced a traumatic event which has increased their levels of frailty and anxiety and reduced their confidence. This point is discussed widely throughout all the focus group data, for example during the staff group the participants discussed the importance of introductions with patients and recalled prior experiences that they consider to be poor

Bethany: I think we just get the basics right here, we say hello, we smile, we ask them what name they liked to be called and we tell them what we're going to do

Sandy: we introduce ourselves as well which is so important

Bethany: yeah exactly, like we've all been on the wards, someone walks over whips back the sheet, has a look at something on their body, doesn't actually say who they are, why they're here, who's with them, we've all seen that happen, it doesn't take any longer, just 3 seconds because you can be doing bits whilst you're saying it. We do the basics don't we? *(SFG line 405–411)*

Staff acknowledge the significance of the receptionist's interactions not only on creating a welcoming environment but also on reducing anxiety that patients may have entered with

Hannah: I actually think it starts at the door because I hear Angela

Nina: oh, Angela yeah

Hannah: and she knows everybody, "hi Bob nice to see you" "hello again how are you today" and then even just as soon as the door is open so they feel like, A) you've remembered them, you know who they are, you're expecting them, they're welcome, so immediately whatever they are feeling they have that warmth flooding over them, from the minute that door opens

Greg: they feel like individuals like that don't they

Nina: yeah I have to say Angela you really do, you really do.

Angela: 70% of patients have no clue why they been referred or what they are coming for, 20% are absolutely desperate and 10% just don't want to know and want to cancel the appointment

Bethany: but you're so lovely with them, and that's what the ward clerk on the ward should be doing, but to be fair on stroke there is a couple that potentially do and do say "hello, come with me" but actually you don't get that on the ward, the ward clerk doesn't do that anymore

Nina: honestly you're so welcoming, and I've seen sometimes when people are late, I see them getting out of their car and the stress of them, and they are trying to get their *coat off, I've watched it happen, they get their coat off and you have managed to turn that round and make them feel welcome, you can see they're calm, you are so friendly and actually… thank you.*

Angela: thank you no worries

Bethany: even when you're on our own in the office (laughs)

(SFG line 422-443)

This dialogue not only demonstrates the insight that the staff have as to the importance of an individual feeling welcomed but also recognition and appreciation for other colleagues' actions, something which is witnessed throughout the observations. Lacey (2015) describes this type of environment as a welcoming space, through the offer of hospitality and an atmosphere of safety she suggests this creates emotional spaciousness which enables an individual to be themselves. Feeling welcomed is a human experience which creates as sense of internal wellbeing and relaxation, literature suggests that people with frailty are already experiencing low self-worth and anxiety (Andrew and Rockwood 2007, Frost et al. 2019), so to create a space where this can be alleviated will lead to more engagement with a person's self and their world. Angela's actions at reception slow down the pace of things for people entering the unit. Nina recognises that this had an impact on the patient before they have even reached a therapist and calming anxieties that patients enter the unit with is a significant first step in their therapeutic journey.

Once registered the receptionist hands the patient a name badge, the badges are pre written and about 10cm square with their full name, the receptionist tends to stand to pass the badge, some patients take it and clip them to their shirt or blouse, others will push their chest towards her as a gesture for her to help, which she willingly does. She offers to take their coat, I have observed that on their initial visit many keep their coats with them, a protection or comfort perhaps as still unsure if they will get them back or remember to pick them up. This links with some of the themes in Chapter 7 with patients trying to balance uncertainty of what is going to happen with the loss of control in their current world. She then leans over the counter and points to an open area to the right of reception where she tells them to wait and someone will bring them a cup of tea. People often sound both surprised and delighted at this prospect as they make their way towards the waiting area. These simple processes appeared to give a positive first impression for people entering their rehabilitation journey.

The overriding sense when entering the Day Hospital is one of welcome and comfort. Both the environment and the processes carried out by the staff provide a supportive space for patients to begin to relax and adjust. By nature, hospitals are stressful environments, older patients with frailty are entering these environments not only with the anticipation of what may happen but also reduced intrinsic capacity by the nature of their condition of frailty. By recognising these stresses and providing a supportive welcome the staff offer security and orientation with an aim to create a positive experience for all. The welcoming reception provides a sense of place to patients who may feel frightened or insecure. As a physical space it feels safe and friendly but the sense of security spans more than just its physicality, the comfort and familiarity demonstrated by the frontline staff offers patients and their relatives an opportunity to start building connections and feel grounded at the start of their journey through the Day Hospital.

8.2 Hospitable care - Never underestimate the power of a cup of tea

The waiting area is a large room which opens from the corridor alongside the reception area. As you walk in, to the right, is the therapy office where nurses, occupational therapists, physiotherapist and assistants are based. There is an entrance door and just past the door the partition wall that divides this office and the waiting area contains a large glass window from ceiling to hip height which runs the length of the divide. It feels like a shared space, the patients can clearly see into the staff office and vice versa. As patients enter the waiting space they are free to choose a seat, most are at one of the three large tables. Some choose to sit with other patients waiting, some will walk the length of the room to first assess their options. As they sit a volunteer undoubtedly approaches them and asks them if they would like a hot drink and what is on offer. Again, most patients respond in a surprised manner at the offer of a drink, some get their purses out to pay but the volunteers quickly reassure them it is free. Hot drinks ordered, the volunteers head back to the kitchen to prepare and a conversation often ensues between patients and relatives or others on the table about how nice it is to be offered tea, this also often leads on to conversations about food or general chat for example in the field notes I noted

A woman on her own sits opposite reading a magazine. The volunteer brings her a cup of tea and 3 small sandwiches, she tells the volunteer that it's too many and she is worried about not finishing them, she turned to the couple and offered them a sandwich she said it's nice to be given sandwiches and they are very good. They have a conversation about different sandwiches, and they agree that Marks and Spencers do nice sandwiches, but all sandwiches taste better when someone else makes them for you.

(Taken from field notes April 2018)

Over time it is evident that volunteers and patients develop rapport. On several occasions, I witnessed volunteers recalling a person's preference for tea or coffee, how many sugars they have or whether they prefer cake or a biscuit. This waiting area is a hive of activity and interactions, and I found myself spending many hours there, working alongside the volunteers making drinks and serving lunches. The sense of hospitality within the unit is strong, people are eating and drinking, and it generally feels very relaxed.

The feeling of hospitable care is replicated in the staff office daily. Barely an hour goes by that someone does not offer to make drinks for everyone, over the months I rarely witnessed someone appear with a drink for themselves having not offered to others. The process of drink making did not appear to carry any hierarchal status within then group, the offer is universal, all grades of staff are makers and drinkers. This was also noted in the staff focus group during a discussion regarding the welcome that people experienced.

Greg: well yeah absolutely because I've worked in all sorts of environments on nights, the admissions, A&E and people that I've admitted over time, when I come here I spoke to the manager and asked if I could come and have a look around as this is totally different to what I have done for the last 40 years, and nobody knew me apart from the odd person, I was dressed in my own clothes, and the moment I walked through that door there was this warmth and this smile and then beginning to work here that goes all the way through from the reception, taking their coats the cup of teas going through to the nurses and physios doing their treatment it's genuine all the way *though and then they come out and it still continues, each one of them feel they are an individual and when I have admitted people on to the admissions ward and everything else, they so feel like a number*

Nina: hmm, bed 3 bay 4

Greg: they want a bedpan; you'll have to hang on a minute. Here if someone wants a cup of tea anyone will make it, so here its genuinely from the moment that smile when I came in through the front door all the way through and its genuine and its lovely

(SFG line 269-282)

Greg's experience of his own welcome to working in the Day Hospital in comparison to other areas in the trust had created a lasting impression on him. For him the equality throughout the staff in the 'simple tasks' created a sense of value for patients and respect for the staff.

Some of the staff enact this hospitable role more so than others, one assistant appeared to be the go-to person for comfort. She is particularly tactile and would often touch the patients whilst they walked to their seat or when she asked them a question. She is physically quite short, but I often noticed her crouching on the floor when speaking to patients who were seated. Patients quickly picked up on her nature and would comment on how kind she is. In the office she was often the first to offer help to anyone who looked busy or stressed, asking them if there was *"anything she could do for them".* Over time I found more significance in her use of "them" at the end of that sentence. The offer is a personal one, of personal support in whatever form. It appeared that the simple process of this question being asked was enough to ease some of the stress of the individual; the knowledge that support was there if needed appeared to reduce the tension that people felt. Being there, not necessarily doing something was important.

The sharing of food amongst the staff is of significance and something I will address in more detail later, but this assistant has become known as someone who will have emergency supplies of food for apparent comfort. During an afternoon lull it is commonplace for staff to approach her and ask for food or snacks. Over the months I also noted her have medications such as paracetamol or sanitary products which she told me she brought in to share if anyone needed. She had adopted a motherly role to the other staff who appeared to both accept and at times rely on her acts of kindness and comfort.

The provision of food and drink in the Day Hospital creates a homely environment. It is wholly unexpected by patients and relatives but always warmly received. Staff and volunteers remembering a patient's drink choice promotes individuality and supports the patient to feel a sense of value in their presence on the unit. Clinically, ensuring older people have adequate food and fluid intake is essential for maintaining their health (Burns 2016). This service however provides more than nutrition, it nurtures communication pathways across groups, staff, volunteers and other patients and relatives, relationships are developed over a shared drink, it is relaxing and social and a familiar activity for patients to participate in. Having a cup of tea is not only physically restorative for older people after their journey to the unit, it is a socially familiar process. By establishing socially familiar rituals at the start of their journey it appears that patients are more relaxed when they start their therapy.

8.3 Environment – fostering a healing sense of place

Throughout these findings I have identified that patients and relatives come to the Day Hospital with preconceived ideas of what a Hospital is like. During the observations there appeared to be a consensus that patients were generally thankful for the clinical care that the main Hospital and their GPs provided, however it was also expressed that how that care was delivered at times, felt unsystematic and unpredictable. As a society we are continually exposed to the failings within the NHS in the media (Francis 2013; Department of Health 2013; Inman 2019; Triggle and Butcher 2020). Many patients had personal or anecdotal stories of something '*bad happening to them*' in hospital. The site that the Day Hospital is on used to be the workhouse for the local area, some patients remembered this from when they were children and associate the workhouse with the very poor, homeless and 'Tramps'. One commented that they wouldn't live in the houses next to the site as they are haunted, they seemed quite clear about the type of person who used to be there but didn't make any obvious association with the Hospital and the workhouse now. In a previous role a few years ago I had a very hard time persuading patients to be transferred to this site for rehabilitation as many had memories of the workhouse as somewhere people went to die. Although that generation has now mostly passed, these pre-existing thought processes and schemas can add to the anxiety that patients feel, therefore the physical environment can play an important role in a person’s view of how ‘things work’ and what may happen.

Over the observation period it became evident that the physical environment of the Day Hospital played a significant role in the culture of the unit. The initial sense of space and light described is replicated throughout all areas populated by patients and staff. There appears to be two main communal areas one that is generally occupied by staff (the therapy office) and one that is mainly occupied by patients, relatives and volunteers (the waiting area). Both areas are adjacent to each other and separated by a wall which is glass at the top and brick at the bottom.

Figure 20: Connecting window between therapy office and waiting area

Although the two rooms are separate it feels that the groups share the space as they can both see in ‘each others’ areas, although the patients do not freely enter the staff section.

Many of the general conversations amongst people in the waiting area involved discussion of the environment. Patients and relatives reported that spaces, colours and pictures within the Day Hospital made them feel “happy” and “cheerful” and that this made their experience “less like a hospital”, with the associated negative connotations.

Woman sat alone in waiting area reading magazine. I sat down with her and she started the conversation.

“It’s nice to sit here with all the colours, it’s cheerful isn’t it. I came before but it wasn’t like this it was drab”.

We talked about how the hospital had been renovated generally and how things have been updated in the last 20 years. She explained that she lived locally all her life and had seen lots of changes taking place. She said that she had an uncle who had stayed in the hospital for months, now people are in and out so quickly.

(Taken from field notes 15th December 2017)

The patient’s discussion around prior experiences of the Hospital suggest a predetermined expectation of what she was expecting the hospital to look like, the use of the word ‘drab’ infers that her expectation was one of dullness and lacking interest. During the staff focus group Bethany, a physio, described her prior experiences of a Day Hospital

Bethany: it’s interesting that other Day Hospitals are closing because as a student I worked in another day hospital environment up in the Midlands and basically I remember it as being grey, do you get what I mean, so it was grey, people were running around doing infusions, people were running around doing blood tests, yeah there was a little bit of therapy but it didn’t all link up. Whereas here its bright pink and bright yellow, and smiling faces and cups of tea and there’s a radio and everyone’s eating and drinking

Nina: yeah

Bethany: the environment, I think that’s all part of it as well, and then us all linking up together and being in the same office without blood tests and infusions and all this other stuff going on I think does help, because if you put a colour to this this is yellow and what I remember I remember grey

(SFG line 255-265)

Bethany felt that the bright colours create a positive and more cheerful memory of the unit and links that positivity to the welcoming actions of smiling and hospitality provided. It was also felt that there was a togetherness that comes from all members of the multidisciplinary team being in one office.

The word ‘cheerful’ was used numerous times in conversations about the unit

Many people comment on entry to the Day Hospital that ‘it’s lovely’. One woman said “it’s so lovely and bright, all the bright colours and pictures I’ve never seen anything like that before. It makes you happy cheers you up.”

(Taken from field notes 10th December 2017)

I also noted that discussion of the environment often started a group conversation in the waiting area

I have found myself being drawn to groups of patients that engage in conversation with each other, I have noticed that often the groups that tend to do this appear to be of similar age and seem relatively physically well at first sight. It seems to often be groups where there are relatives at the table as well.

This table was a mix of male and females who all appeared to be in their 70/80s, two of the group didn’t have name stickers on them so I assumed they were relatives. They were having a conversation about the renovations at the day hospital and what an improvement that it was to them from previously. Most of them referred to the fact that they had been there previously and that it was such a change however I was unsure if they meant to the previous day hospital (which was a different building and area of the hospital) or they just generally meant to the hospital. Either way, the change of environment appeared to be of significant interest to all in the group, and as they spoke they were looking around the room.

Pt1: I’ve been coming here for lots of years for different things and they have spent a lot of money on it (referring to the renovations of the hospital).

Pt2: it’s fantastic isn’t it? So bright. No complaints now.

Pt1 yes the staff really are fantastic I think it’s great.

Pt2: and you get lunch and a nice cup of tea, it’s got a good reputation, everyone I speak to thinks it great. *(Taken from field notes 23rd January 2018)*

The conversation then moved on from the environment to the staff and the treatment that they receive, and that the Day Hospital has a good reputation. Again, they acknowledge the importance of receiving refreshments as a defining feature of their experience. There was a sense that the positivity felt from their surroundings supported shared experiences and allowed for conversation and engagement with those around them. This particular conversation led on to more personal discussions about their conditions and treatment at the unit, there was an element of self-comparison between members of the group, however this was a positive comparison i.e. the focus was on how much benefit that they had received from the treatment and the exercise rather than direct comparison of the things that they had wrong with them. Their journeys were discussed with a sense of hope and positivity through the treatment that they were receiving and being able to share this with others seemed to compound the positivity.

It appeared that having a cheerful and colourful setting led patients to feel more positive and engaged with their situation. The space feels social, there is noise and chatter and smiling. Over time strength of the impact of this finding grew as I witnessed the sadness that patients portrayed as they came to the end of their treatment sessions, many of them commented on missing the hospitality but also seeing the garden and bright colours.

The Day Hospital has been recently refurbished, and all the communal waiting areas are painted in bright, striking colours. There are also large prints of local scenery around the unit. The main waiting area is the busiest in the unit, there is often a lot of background chatter and a stereo which seemed to mostly play Radio 2. During the observational period I chose to spend much of my time in these communal areas as they were highly populated and provided depth of data. During one observation a table with a large group of women were seated, they stood out to me as there were speaking much louder than the other tables. They seemed to be talking more as a cohesive group rather than just speaking to the person next to them, all seemed to be involved in the conversation. There was quite a lot of laughter, I decide to go over and make conversation with them. I was quite surprised to see that all the women looked quite old to me, their loud laughter didn’t seem to fit with my idea of that age group and indeed my experiences so far at the Day Hospital. It was an interesting moment that made me reflect upon my own norms about older people having fun.

The group easily accepted my presence and continued talking as I sat down on an empty chair. They were referring to items on a bric-a-brac table which is in the Day Hospital and raises cash for the petty fund. The act of shopping at the bric-a-brac table had brought a shared sense of laughter to the group and looking around the room other people sitting in the waiting room were laughing at the group laughing, it had become infectious and felt joyful. This is quite an unusual feeling in a Hospital perhaps, which is why it felt so noticeable. There is a real sense of shared experience as they are all waiting for the same thing. Perhaps the loudness of the group somehow gave people on other tables permission to talk or encouraged/empowered them to do so. Perhaps it was simply the mix of the personalities on the day. Laughter can be seen as a universal communication which translates across different cultures and languages generally relating to happiness and joy, a number of authors also highlight the benefits of laughter to wellbeing in older age as they argue it can increase mood and reduce anxiety and stress (Berk 2001; Mora-Ripoll 2011). By providing a milieu where older people can feel safe, relaxed, able to openly communicate and express joy, the Day Hospital lays the foundation for the older person’s world to begin to rebuild its connections following the losses described in Chapter 7.

Overall, the physical environment appeared to play a significant role in supporting positivity by providing a space which is cheerfully engaging, feels safe and welcoming and different from preconceived notions of a hospital environment. Bright colours and pictures of local landscapes appeared to lift mood and generate conversation. Patients and relatives some of whom had not left the house for several months seemed to reconnect to their local environment, recalling places they had been and shared memories of the area. Laughter was commonplace amongst both the patients and the staff, and the soundscape of the unit, that of mainly chatter and music, rather than other clinical sounds usually associated with Hospitals, was accepted and encouraged.

8.4 Building relationships – presencing

In both the observational phase and the focus groups the presence and importance of relationships across several groups and individuals was evident. From the start of their journey through the doors of the Day Hospital, patients describe feeling welcomed, being included in assessing and planning their treatment and feel that they are known as individuals. Each patient is allocated a key worker and named therapist from each of the disciplines nursing, occupational and physiotherapy which they should see each week.

Henry: Yes definitely the way, certainly myself when I first came to the falls clinic, the way that I was welcomed for a start off, the way that the erm physios looked after each individual and I think there was about six or seven of us in this particular class, erm, each one was cared for by the physio therapists and its had a lasting effect on me and that was initially two years ago.

James: yeah I quite agree with that, I quite agree, they've all been brilliant the ones I've seen yeah. Even right from the receptionists, you know.

Henry: yes yes yeah (PFG line 8)

Even within a group environment patients felt treated as individuals. James' reference to the receptionists not only supports my observations of her actions but also perhaps infers that this level of individualisation is not expected from all staff by the patients. This may be a social perception as Greg infers in the staff focus group about receptionists.

Greg: but it's very true, what are our experiences of going into the GP surgery? We all see the receptionists, there's a stigma about the receptionists, but when you come in here it's the same thing, they think oh I have to go and see the receptionist, I hope she is not like my GP receptionist and then they are like wow, bang.

Yeah yeah

Greg: and that's what I felt when I first walked through that door to have a look around. Hi how you doing? I can't remember who it was but three of you, and then big smiles and it was genuine you know, wow, and it's a follow through and it's so different from the main hospital and a lot of things in life and this is why we are a winner here, that's *what I see just in a short time how much different it is.*

(SFG line 444)

During the observational phase patients and relatives would often pass comment to each other about particular staff members and the way they made them feel. Many times, people commented on feeling sad that their sessions were coming to an end and that they would miss the unit and the relationships they had developed.

With this the physio returned with a stick she had fitted a new rubber end on to it. He said to her "that's a clever girl how did you do that". The physio laughed and looked a bit blushed and explained that she had to get someone to help her fit it as it had ridges and got stuck. The man continued to seem pleased regardless. The physio explained that she wasn't able to see him next week but that someone would see him instead to cover her but that he would hopefully be discharged as the other disciplines had already discharged him. The man looked disappointed and jokingly quivered his bottom lip; he said that was a shame as he felt he had got a lot from the sessions. The physio reassured him that whoever was covering would be just as good. She said goodbye and went to the office.

The community car driver said that he hadn't done many visits to Christchurch latterly and commented on how it had changed. He said that you must have lots more services here now as we seem to be coming here much more often. He said

"It's lovely though we don't get a cup of tea anywhere else when we wait for our patients"

The man who was being treated agreed that the services were really good and that he didn't know it even existed. The driver stood up and said are you ready to go. The man got up and they said goodbye, the driver said thank you for listening to my story and they left. *(Taken from field notes 30th November 2017)*

This patient comments on it being a shame he must finish his sessions, during the observation period I noted that having the same therapists each week seemed important to people, that it provided a sense of security and that people were able to develop bonds. Patients also commented that it meant they didn't have to repeat themselves; this point was also discussed in the focus groups.

Sam: But that is the fact that yes, I shall certainly miss the fact that if anything's cropped up, like I say it has, we know that, it's not easy to get the continuity in our own doctors' surgery

Cathy: no no

Sam; so I go and see one doctor and he says what was it you're here for, and then we go through it, then all of a sudden he's not well, so we ring emergency surgery yeah well fit you in, so you know so we haven't got continuity, whereas here yes we've had one or two not that it's been different people but they all seem to know the continuity of what's happening. Which a lot of us I'm afraid not get in our Drs' surgery

Moderator: so do you think they talk to each other?

Sam: well I think they must do because I know it's not as if Jim brings the book every Monday, but they seem to know what's going on, you know, they don't make you feel that you know you're talking to somebody, oh well we didn't see that nurse last week but she seems to know exactly what she should be checking .

Moderator: how does that make you feel then?

Sam: well I've got continuity, I'm not coming over and meeting someone again the next Monday, were following its on you know it's a bit of a journey isn't it

(RFG line 76-92)

Here Sam describes the feeling of continuity in her husband's care, and that having the same therapists and sharing information with each other meant that they feel valued, listened to and invested in. This is also different to the other experiences of healthcare they have had at a time when they have high levels of stress and are trying to balance multiple life changes.

During another observation a woman was chatting to me about her therapists.

A physio walks past and smiles.

"That's the physio, she's great, she is very strict but wonderful, she had me walking and she doesn't give up on you. She hasn't given up on me she said. I had my arm go with the stroke, but I got that back, I know it's a bit slow but its back now, if only my leg would do the same. I just had no warning one minute I was ok the next I wasn't. I was just found like that. *(Taken from field notes 25th May 2018)*

The woman was 91 and had lived in the area all her life, she remembered the Day Hospital when it was a workhouse and orphanage and how it was full of "tramps and homeless".

Opposite used to be the childrens' home and opposite that used to be the cottage homes for orphans. All the Americans used to come and leave them. It's all changed here you can see it one week to the next"

(Taken from field notes 25th May 2018)

She talked about how people were just left there. I found significance in her reference to the physio not giving up on her, in a way this felt relevant to her memories of the building and how it was once somewhere were people who had been given up on came. Her use of the phrase "she doesn't give up on you" might suggest that she feels that other people in her life have given up on her, or indeed she had given up on herself. The feeling of investment from the physio in the patient's therapy achieved not only positive physical outcomes in terms of the use of her arm, but also a sense of achievement and reduction of hopelessness that she may have felt or related to the building as she related the orphanage to the Day Hospital. She was hopeful that the use of her legs would return.

Feeling listened to was discussed on numerous occasions as a process that made people feel valued and individualised. Referring to the assessment and goal setting process at the start of their journey Brenda, a patient, highlighted how she felt part of this process.

Brenda: and I think even the paperwork before hand, setting achievable realistic goals, so you actually thought yeah I've done that, sometimes you've gone beyond that goal and that makes you feel really good.

Moderator: did you feel that you were a part of setting those goals?

Brenda: very much so

Henry: yeah definitely

Brenda: I mean I was on a 1:1 and I was listened to completely and it was put in the booklet

(PFG line 16-22)

Feeling listened to was also raised by the relatives who would come with their loved ones to the Day Hospital. As previously discussed, their arrival to the unit has often followed an unexpected health event which changes their life dynamic. These changes bring anxiety and worry for both parties but the process of involvement of the relatives was identified as a benefit for all.

Sam: well I can only, I'm Sam, can only speak highly of everything , my husband obviously had a stroke late November and we were in hospital for a little while, you go home and then you think, what do we do if, what do we do if, then all of a sudden this letter arrives inviting us here. I've now become the main driver obviously so we come, and we come for the assessment and you're greeted with would you like sandwiches would you like a drink? And to me that was absolutely, that's been the main thing involving me as well, erm very comforting for Jim because we have had a bit, were still having a bit of a journey and everything is answered, if they can't answer it they will go and get somebody who can . And you're covered with these three lovely girls , and I must admit even the receptionist when you stepped in to the lovely women that do the soup and sandwiches it's been, we've sort of felt that if we've got a problem in that week, and we have had quite a few, that we know we'd come in to the stroke clinic on Monday and we could talk and they listen, Jim is only, he's 77, so reasonably young and we've seen lots of people and we've talked to people and I can't speak more highly of the actual coming and the feeling that if we've got a worry, and we've had a few they will look after us . So really I can't thank you enough. *(RFG line 8)*

Referencing the hospitality they received adds to the feeling that they are being comforted in this difficult time, having their questions answered or knowing that they will be creates a sense of security for the couple at a time that they feel overwhelmed. Again, the reception staff are mentioned which suggests the concept of being listened to by all staff is important for patients and their families, even if they cannot directly do anything, being able to share their journey, story and fears is deemed important.

Patients and therapists alike appear to form what feel like close, genuine bonds with each other. This is evidenced not only in the observations but also written in the feedback forms from the patients. These feedback forms are ritualistically read out once a month at the staff meeting and there is real delight for each other when a colleague is specifically named.

The manager had a list with feedback on it. She states that some people's names have unfortunately been blacked out as the patient may have been confused and ticked the wrong box, but she continues to read out positive comments to the members of staff written by patients. There is a slight sense of anticipation on the room; people start to look at each other as names are read out. There are many noises such as 'aww' and 'ahh' as people listen to the comments. When the manager has finished reading out the comments where specific staff members are named she holds another piece of paper up with more generic comments. It appears to be a ritualistic practice in the meeting that the paper is passed around the staff members and they are asked to read aloud the comments. The paper is passed around the staff members and they read 2 or three comments each before passing it to the next person

(Taken from field notes 21st November 2017)

During these meetings there is a sense of shared pleasure and pride in the work that the staff are achieving, the meeting is always ended by reading these positive comments and staff seemed to be motivated by this starting their day.

During the staff focus group the importance of building therapeutic relationships with patients and relatives was discussed. As previously mentioned the process of welcoming people in to the unit was recognised as important, but another element of trust was also raised.

Greg: I think its initially, been following my mentors and stuff it's how you first approach that person, we all have different professional and jobs and uniforms and stuff but listening to my mentors and stuff it's that first initial approach, putting aside right I'm going to take you down the room going to do your bloody pressure etc, it's that initial how are you? My names Greg, welcome to the day hospital, if there's anything that you need just ask, if you want a cup of tea. It's who I'm about and this place, what I'm going to discuss, and nurses will discuss after me is second to that initial first introduction. You can see their faces, look for their name tags, like when you're called Mr so and so it's like being called in to the dentist when you were a kid (gasps) panic, panic, panic. But yeah initially that first introduction they've seen the smile, they've been given a cup of tea and cake, then the nurse approaches them and my approach with them is just *literally getting a bond with them, taking time to find out a little bit about them, you know their day and stuff.*

Nina: so technically we would call something like that having a therapeutic rapport with someone wouldn't we, having a therapeutic rapport and trust, and I think trust, because I've always done it that's the thing, even in that really fast paced environment out of here, it's looking at someone as a human being. Yes I've got a uniform on, yes I'm here to enable you to do stuff, but we're both human and actually that first interaction for me is all about trust, it's all about trust, if you haven't got trust you cannot operate, you cannot do anything if they don't trust you. *(SFG lines 386-404)*

The acknowledgment and validation of people as individuals and the need to develop a therapeutic bond for people to feel relaxed and trusting appears to be an underlying thought process by most staff and volunteers in the unit. Nina made it clear that gaining the patients trust was an important process in her therapeutic relationship with them, throughout the observations the sense was not only that staff and volunteers aimed to gain patient trust, but they did so because they recognised the feelings of the patients entering the unit. It is evident from both the observations and the focus groups that patients enter the unit with a certain level of vulnerability and fear as discussed in chapter 6. A culture has developed within the unit of holding a space for patients to acknowledge how debilitating their conditions such as frailty are. Acknowledging these limitations and vulnerabilities appears to enable patients to move forward in their journey. Hannah talks about her experiences of this during the focus group

Hannah: Yeah because they may not have anyone to say those things to them and personally from a clinician's point of view, I always think it's important to recognise people's fears, to acknowledge them because for me that's how I work well if someone acknowledges something, so perhaps the acknowledgement. I've actually had a lot of patients become very emotional with me just because they say I finally feel like somebody is listening and I finally feel like someone understands and that actually, they just break down, that's what they need to do and they think that finally someone is understanding and really realising how debilitating those anxieties and fears and how real they are and how they impact on every single thing they do and then we build from there don't we and we build that confidence and reassurance *(SFG 240)*

Both Hannah and Nina describe a process whereby the acknowledgement of the patient's difficulties, without feeling the need to take over or 'sort it out', is a crucial start point for the development of therapeutic relationships and engagement in rehabilitation. There is a sense that the staff and volunteers are nurturing both the patients and the relatives through the journey they are experiencing in order to move forward and progress. Building trusting relationships creates a sense of safety for patients and certainty in their world which is often uncertain. For patients who appeared particularly anxious I noted that the first few treatment sessions were often less regimented than for others, on one occasion the nurse told me that they were "just going to talk about windsurfing because it relaxes him". There is a strong sense that staff believe in making the patient feel relaxed first and foremost, there were times of course that staff came in to the office and felt 'behind' with their work as the patient had directed the conversation in a different direction for example. What was notable form the times that this happened was that other colleagues would support this, and I would often observe them creating a joint plan in order to fit the therapy needed around the pace of the patient.

Goal setting is a core part of the therapists work with the patients. The unit's assessments are based on the comprehensive geriatric assessment which is currently considered the gold standard assessment in older person's medicine (British Geriatrics Society 2014). I observed a number of these assessments during the data collection and over time it became apparent that the staff do not simply see it as a process of identifying need but take it a step further by facilitating the patient, where possible, to firstly identify needs that are important to them, and secondly to explore and provide acknowledgement for needs that the patient may not have recognised as being something they can improve upon. During the assessments patients tended to start by talking about leg exercises or physical movements without relating them directly to functionality, for example when asked about functional tasks around the house patients tended to speak about how they mobilised from one room to another rather than the task itself. Although mobility is important, recognising the restrictions in the functionality of their day to day lives seemed at times to have been forgotten. The assessment staff were skilled in exploring a patient's daily life in a relaxed manner in order to extricate extra information that would help the patient rehabilitation.

During the assessments staff would also ask about things such as taking the bins out for collection or hanging the washing outside on the line, these were activities that many patients had lost functionality for as they had become frailer, it was almost as if they accepted that these losses were what happened as they got older and didn't realise that were potentially modifiable. During one observation a physio explained these assessments to a student

Physio: "it's not about us and our goals for them, it's about her and their understanding and can they identify what's going on with them. But we look at what we can do about things, what we can help and how their problems are impacting upon them. "

(Taken from fieldnotes 8th June 2018)

I feel this quote really summaries the assessment process at the day hospital. The focus is not about the therapist and the importance of their goals for the patient, it is about supporting the patients understanding of their life, what is really happening within it and how the setting of goals can help to improve things. They focus on capabilities rather than problems and look to embolden patients to develop these capabilities.

Throughout the unit there is a strong sense of empathy with the patients and their relatives; one example was when staff were discussing the process of referrals for dementia diagnosis.

An OT was speaking quite loudly and at length to a patient on the phone this morning, as the conversation went on the OT appears to be getting more apologetic and flustered in her speech. She seemed to be explaining a referral process to a patient and was apologising that they hadn't previously been told that information. When she finished the phone call she seemed frustrated and started a conversation with a Physio sat near her. "That was Mr Brown again, this is the 3rd time he has called about his memory referral and he has phoned the service and they said they haven't received it". It transpired that Mr Brown had not been told in full what the process of the memory service referral may be and therefore expected something to happen very quickly i.e. within a few days. The referral hadn't even been completed by the OT and she knew that the whole process would actually take a number of months. She was saying to the* *physio how ridiculous she felt the whole process was as she felt that it left potential for patients to deteriorate quickly within that time frame. They continued to have a conversation about how hard it is at times to manage patient's expectations, but she recognised that she should have explained the process better to him. I sensed that the therapists were advocating for the patients, they recognised that the processes were long and felt sorry for the patients that had to wait that length of time. I sensed from what they were saying that they felt a bit stuck in the middle and found it difficult to manage external parties and their timeframes when they had the direct contact with the patients. Mr Brown had anxiety, which the OT said is very common in people with memory loss, and his anxiety was heightened by this situation. The OT said that she felt that she should have explained it better and then he perhaps wouldn't have worried so much about the situation. (Taken from field notes 27th April 2018)*

The therapists seemed to suggest that the process was unfair and that they wanted patients to be seen quicker, that they would be willing to support this but that they were restricted by third parties. The consensus was that the delays may contribute to the opportunities for the patient to remain independent.

During the staff focus group great empathy was shown when talking about the patients and recognition of their courage for engaging in rehabilitation. During the staff focus group I questioned what they see in the patients as many enter the unit with similar issues.

Moderator: because maybe everyone is coming in with similar type problems? But you're seeing the capability? Would that be?

Nina: we are seeing where they can go, where they can go

Bethany: yeah I think that's the reaction, what goal can I set for you to achieve

Hannah: yeah, were always looking for what they can do rather than what they can't do

Nina: and we understand the limiting factors, so something like fear, fear of falling its huge, once you can address it honestly and say to people, you know, let them understand that you know their fear is huge, who wouldn't, lying on a cold floor wondering if anyone is going to come and get you, you think you might die on that floor, is anyone going to come, that time gives you thinking time and you become frightened, and addressing that, and then they start to relax and they start to move better , and they get a bit courageous, you know, and they decide they are going to take, and every

> *week they get a bit better and I always say to people, oh you seem to be getting up a little bit better today and building, I think the beauty of here for me is the fact that I get time over weeks and I can see incremental changes and progression , and to be able to feed that back very briefly to someone, you know you seem happier, you seem this you seem that It's great, it's so nice*
>
> *(SFG 225 – 238)*

This dialogue highlights how small incremental changes are both praised and valued which in turn promotes a more positive self-image and sense of self efficacy for the patients during a time where previous research suggests that their sense of self is often very poor (Andrew et al. 2012; Twigg and Martin 2015).

During the observational phase it was evident that the hospitality provided by the volunteers offered comfort and a warm welcome to patients, it was not until the volunteer focus group that it was evident the depth of these comforting practices. Gemma discussed a time where she offered comfort to a patient.

> *Gemma: or you get a little old, well not so long ago about 2 or 3 weeks ago, a little old woman came in and she was sitting there sobbing because it was the first time she had come, she knew nobody, so I just sat there near enough the whole morning just holding her hand . When she came in the next week she made a point of coming to say thank you, I needed you then.*
>
> *People say yes*
>
> *Gemma: and that's part of the job, just being there.*
>
> *(VFG line 83-39)*

It is interesting how in this example Gemma describes the patient as a 'little old woman', a comment which seems indicative of how some of the patients are seen by the volunteers. There is a vulnerability seen in many of the patients that the volunteers look to lessen through comforting behaviour. Gemma sat with the patient for several hours, the support was both emotionally and physically ongoing through the holding of hands. She fulfilled a need she saw in the patient and that was acknowledged by the patient subsequently. Gemma's understanding of the issues that patients coming in to the day hospital face helped her recognise what support this patient may benefit from. The last sentence “and that’s part of the job, just being there”, highlights how being present with the patient in their moment of need is recognised as an important role by the volunteers and reflects practices of the staff.

Moderator: so in terms of your role in relation to the day hospital, apart from serving the food and drinks and things is there anything that you see as an essential part of your role here?

Pause

Gemma: I think the thing really is just caring, having that caring side and the willingness to go and talk to the people, you know, we could be sitting up one and everyone is down the other you have to make that point of going down and mixing, interacting with the patients.

Bernie: I mean some people want to chat more than others don’t they.

Gemma: yeah, yeah, if they’re having a conversation on a table together then they take one step back as they are enjoying themselves, but you’re always going to have that one person on their own and that’s the person that you make sure you go and give them the time *(VFG line 118-127)*

It is a very human reaction to sit and be with someone who looks distressed, the volunteers mentioned on several occasions how ‘busy the nurses are’ and seemed to consider themselves as somewhat of a go between them and the patients. They assess the situation and make time for patients. Gemma identifies caring as part of their role, the concept of caring through presencing or ‘being there’ in this way is seen by some to be fundamental to nursing practice. Through being present with the patients both the patient and the staff member can feel recognised as human beings sharing an experience.

Building and developing therapeutic relationships appears to be a core process undertaken by both staff and volunteers in order to enable patients the opportunity to acknowledge their abilities and develop these therapeutically through rehabilitative process. Building trusting relationships is recognised as a key element to care provision and it is accepted throughout the unit that this can happen in several ways. If set goals have been changed or not achieved one week, there is no reprimand for patients or staff. Therapists support one another to be dynamic and evolve the original plans in a human way. By spending time with patients and their relatives both staff and volunteers can gain a deeper understanding of the person/family and likewise the patients and relatives feel that the staff are open with them. Power dynamics that have traditionally been seen between older patients and clinicians are purposefully negated through the actions of the staff. If anything, there is a sense that the patients and relatives are the ones in the driving seat. Volunteers dedicate time to building trust with the patients, they are observant and intuitive and support the therapeutic work that the staff do by presencing themselves with the patients during their journey. Patients have time to adapt to their new surroundings and to feel cared for, valued and engaged.

8.5 Shared journey and togetherness – processes that embolden and uplift

The value placed on human connections became more evident the longer I spent at the Day Hospital. In addition to the welcoming spaces and hospitality I have discussed, there was a strong sense of togetherness across multiple groups and individuals that I encountered. It felt stronger than the sum of everyone simply feeling happy because they had a cup of tea and a comfortable environment, so I looked to explore the process that may have been creating this sense of togetherness.

I am going to start this theme by looking at the staff; during the focus groups the sense of shared journey and togetherness was expressed in a much clearer way by the patients and relatives however I was able to observe multiple processes initiated by the staff, which largely contributed to these feelings. As previously discussed, the team is made up of several disciplines at varying professional levels, there appeared to be a core team of staff who had been at the Day Hospital many years some 20+ and then rotational therapists who came every 6 to 12 months. These therapists were generally younger and worked at a lower grade to the permanent staff but always seemed to be welcomed graciously into the group without evident discrimination. Supportive teaching practices were clear, new staff had supervised inductions and questions were welcomed at any time. When I started my observations, it appeared to be a difficult time for some of the staff as several changes were happening due to winter pressures in the main hospital. I went to as many staff meetings as I could, during one of the meetings an issue was discussed regarding the assessments

People filter in to the room and bring their lunches with them, some open sandwiches some have hot dishes from the canteen or that they have heated up in the microwave. People are chatting and seem relaxed. People pop in and apologise and say I'm just going to grab my lunch. Within a few minutes everyone seems to have settled and a natural quietness prompts the nurse who instigated the meeting opens and thanks people for attending, a number of staff members speak out and say thank you for arrange it to the nurse as we haven't had a meeting about the assessments in a long time. There are general signs of acknowledgement and agreement around the room. The nurse has a list of items, an agenda, but said that she didn't want it to be that it was all her that was bringing up issues. People said 'no please I'm sure it's all the same issues that we are thinking'.

N: What is working well in the current assessments?

OT (senior). Understanding the patient and getting the report, being the person to really give that patient the time that they need.

A problem was identified that sometimes patients were tired out by walking up and down being taken by the assistants to do blood pressures and weights and then brought back to the waiting area which is quite a long walk down the corridor for some. There was a long discussion about the different options that may be available to help resolve the issue. It was suggested that the assistants joined the morning triage meeting with the trained members of staff so that everyone knows who to take in the mornings. The following conversation was had;

PT (senior) - I don't see why we have to have them in the meeting can't we just tell them what we want them to do.

N – I think it helps with the communication if people have background to the patient when they are coming in. It helps. I have seen X, X and X receive patients knowing why they have come in and it makes a difference and a better experience for the patient and makes the patients feel more relaxed.

OT- It's not about identifying issues it's about identifying solutions.

(Taken from field notes 2nd November 2017)

Generally, there was a feeling of uncertainty within the staff at this time, there appeared to have been several changes of both systems and staff (reported to me by one of the key stakeholders). This meeting had been arranged by one of the nurses (not management) and had agreed it with the management team that it could be held over lunchtime. During the morning, people had mentioned the meeting a few times: “remember there is the meeting today”, for example. There was a feeling of anticipation within the team, people were supporting each other to attend the meeting by reminding each other to go to the canteen and get lunch early so that they would be available. I sensed that people felt the meeting might be important and so I thought it would be valuable to attend.

A key issue during the meeting was discussing the roles of the therapy assistants. Although overall much of the conversation felt very patient focused i.e. looking to rectify issues that may impact on the patients, the conversation I particularly noticed was between the physio, nurse and OT. The issue brought up by the OT was aimed at resolving patient fatigue and ensuring time is used most effectively. The conversation that followed showed a difference in the sensitivity of the OT, nurse and physio. It appeared that the nurse was adopting a mediatory role between the Physio and the OT in relation to the role of the assistants and how much involvement they should have in the morning meetings. It felt important for the OT, and others that were nodding around the room, that the patient feels that the staff understand what is going on with them and that the assistants need the same information as the trained staff so that they have a good understanding of why the patient has come in and what their expectations are. This showed that a positive experience for the patient was seen as essential for most staff, and that to achieve this all staff needed to be working from the same knowledge base regarding the patient's condition.

Throughout the observations food appeared to play an important role in interactions within the Day Hospital. As I have previously discussed, the provision of food and drinks for patients and relatives seemed to serve greater purpose than purely nutrition. Staff were not normally allowed to eat in the meeting room, but during the meeting described above they had been invited to bring their lunch, it felt like being able to eat lunch during the meeting not only saved time but also served as some kind of distraction or comfort for people. Staff eating together generally within the unit was a common occurrence which seemed to bring a sense of solidarity to the group. In fact, it became evident over the months that sharing food was a ritualistic process that the staff had adopted to express joy and gratitude to each other. ‘Bring and share’ meals were commonplace amongst and arranged for people if they were leaving or for birthdays. Each member of staff brought in a dish to share and people took time out of their day to engage in this ritual.

There were many small processes noted that created a sense of belonging and togetherness for the staff for example, each person’s birthday is noted on the calendar and a card is passed round and signed by everyone for them. I was surprised that even mine had been added to the list. At Christmas each member of staff is given a gift through an advent calendar system, they are wrapped and personalised by the management and each day staff pick out their named gift.

Figure 21: Christmas gifts for staff

There was a feeling of community spirit within the Day Hospital. In the office there were many pieces of paper stuck to the door inviting people to nights out, wedding reception or birthday meals. Other signs appeared to be there to boost the staff, one that particularly stood out was this sign below

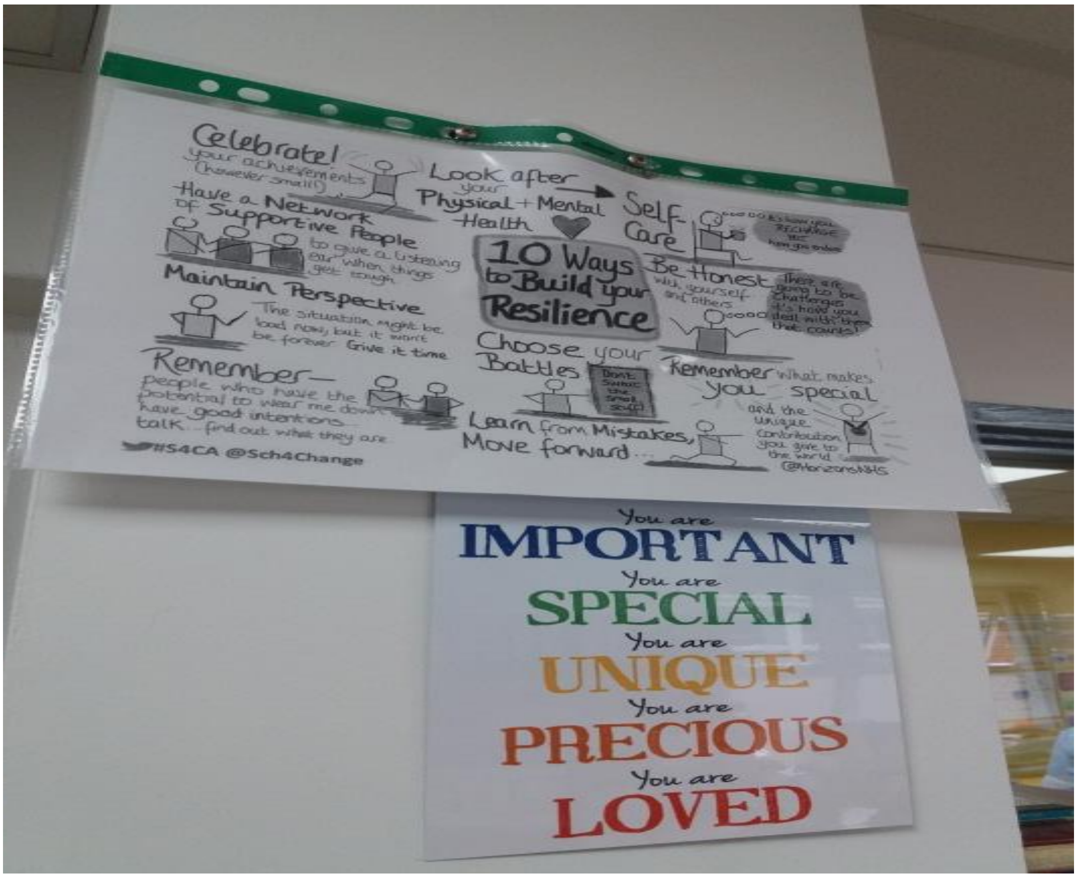


Figure 22: Posters in office

It had a title “10 ways to build your resilience” and focused on self-care, celebrating success and remembering what makes you special. At the time I felt quite emotional reading this message. It resonated with me as a woman, a mum, a carer and a nurse on differing levels. I had never seen such a message in any healthcare setting I had worked. Looking in from the side-lines I was touched by the humanity of this message and the strong sense of the importance of staff as individuals.

Sharing emotions was also common within the office, people laughed often, and chatter was typical. Colleagues frequently greeted each other with a hug, especially after annual leave or sickness. After several months of observations, I appeared to be inaugurated into the hugging culture which, as an innately reluctant hugger, took some time to adapt to, but the concept of inclusivity and acceptance to the group was clear. The window separating the therapy office and the waiting area meant that patients could see the expressed emotions of the staff and vice versa, Gemma (volunteer) referred to this during the focus group as she described one of the ambulance driver's birthday

Gemma: I think that's the thing with the patients as well they can see all that, I mean the other day the ambulance man I think it was his birthday, and everyone was singing happy birthday to him in the office and all the patients were looking you know, and they can see all the nurses laughing and talking as they're going through, you know makes it for an happy environment does it . *(VFG line 465)*

Gemma seemed to substantiate my observations that the openness between the staff and patient area allows for a sort of osmotic process of feeling and emotion. Emotion perforates through this transparent divide allowing for staff and patient to share their mutual humanity. Not all emotion was joyful, there were often times when staff would openly cry in the office, and although perhaps unusual for patients and relatives to witness in healthcare setting, what they would see is supportive and compassionate care between colleagues. Seeing that the staff hold usual human emotions, similar to those some of the patient and relatives are experiencing, enables each group to share in each other journeys. This shared humanity enabled the staff to not only empathise with their patients' problems but also share that empathy, recognising and acknowledging patients' vulnerabilities in order for them to feel recognised and valued. During the staff focus group Nina (OT) describes a time when she was recovering from flu and thought about the patients and how hard it is to really try and understand what they are going through.

Nina: the other thing is by the time people get to us get to us, they know they're finding it difficult, they know they are struggling, everything is just gradually starting to drop and drop and drop and I think by the time they get here they know they need some help, they get this huge 360 assessment that covers everything and then we've got our nice uniforms on, and we know what we're doing, we've got a plan and I think to other people, like I saw a guy yesterday and he said 6 months ago I was walking the dog 4 *miles a day, and it's like I can't understand what that's really like, I can't can I? because I'm, I would say I'm fit, I'm fairly ok*

Laura laughs

Nina: not as fit as Laura and Bethany, you know I can't understand what it's like to suddenly not, it was last week when I had the flu I had to really think about going down the stairs and I was stood at the top pf the stairs really shaky, and I thought maybe this is what it's like for people, they are scared, I was scared that I was going to fall, I'm going to fall down the stairs, but imagine having that every day, every time you go to do something and in every area of your life, erm

(SFG lines 162-176)

Here Nina acknowledged how debilitating symptoms of frailty can be as well as trying to relate it to herself and her own feelings in order to develop a clearer picture of how she may support the patient. Nina was empathetically imagining herself in the patient's shoes, and the feelings of acknowledgment and understanding that this created was evidenced by the patient feedback and their sadness to leave the unit. As a group of therapeutic staff, they adopted this empathetic culture which enabled them to be with the patient through sadness or vulnerabilities and meet them where they actually are in their journey rather than a generic starting point for all.

It is clear from the data discussed the relatives of the patients, who were all also carers, play a vital role in this shared journey. In Chapter 7 Sam spoke about the importance of being included in her husband's plan and throughout the relative focus group the importance of being part of the journey to the relatives was highlighted several times. Sean (relative) discussed how being included in his wife's treatment enabled him to see more potential in his wife, it reduced his fear for her which subsequently allowed for more progression on her part.

Sean: I think that there's a balance, to start with I was probably doing too much, because I didn't want Hannah's risk of falling to be exposed at all, to, what I've recognised from being here is there has to be a degree of independence, for, I'm going to have to use the word patients so it's clear erm so they feel that they are not as vulnerable as they can feel and having , so , I've got as much out if these weekly sessions as Hannah has because its helped me recognise the difference between *being over sensitive and not restricting Hannah's ability to support herself, and its worked brilliantly because she now feels a lot more secure in herself in terms if her physical movement.* *(RFG lines 402-409)*

Hannah's deterioration meant that Sean had given up work to care for her and they were adapting to a new way of living. initially Sean imposed lots of restrictions on Hannah as he felt she was so vulnerable he tried to limit the potential risks, the processes at the Day Hospital has given both Hannah and Sean the freedom to acknowledge those vulnerabilities but also see the potential for progression which reduced he fear and increased independence for the couple.

During the observations, the sharing of individuals stories contributed to a feeling of togetherness, patients discussed their shared losses and achievements, relatives discussed their concern or pride of their loved one as well as sharing their gardening tips or experiences of online shopping. Staff shared their personal problems, their life heartaches and joy with each other, and occasionally patients. They reflected upon the patient's journey and used their imagination in an empathetic and caring way in order to place themselves alongside the patients, in their journey, so that they were able to meet them at the place where they were at and could understand better what was happening. The volunteers created an informal peer support service for the patients and their relatives, they recalled their personal and prior experiences of the Day Hospital to help reassure and support those in need.

Chapter 9 Findings Section 3 - Working within a supportive culture

Throughout the previous two sections I have highlighted the factors that appear to contribute to the identities of older people who are entering the Day Hospital. As they advance their journey through the Day Hospital we can see that many start from a place which is underpinned by multiple losses. These encompass not only physical losses but also social and emotional, and as has been shown the impact of these losses create a situation where the patient and often the relative's world has closed down around them. As patients and their relatives progress through their journeys they being to encounter processes which appear to unravel, illuminate and understand these losses in ways which allow them to feel acknowledged, at the place they are starting from, but also hopeful and importantly motivated for progression. In this chapter I focus on the cultural and societal influences I observed that impacted the overall experience of their journeys, how staff cross inter-professional barriers in order to support the patient in an embodied manner and how a sense of community is created through personal engagement.

9.1 Identity - The casting of roles, social comparisons.

The concept of social comparison, or comparing oneself to others, is closely linked with the previous themes identified. I have discussed how people have had to change life roles and explore new social identities in an attempt to rebalance their lives and maintain independence. In addition to this, patients and their relatives compare themselves to those around them in order to maintain their understandings of their social roles and display these to others. When entering the waiting area for example, people would often look around the room appearing to assess the people there before deciding where to sit rather than heading for the first available seat. Initially I didn't see this as particularly relevant but over the months and through more conversations I noted that many people wanted to establish themselves as well, capable and independent and wondered if their physical placement within the waiting area was some way of distancing themselves from people that they considered to be different to them. By comparing themselves to others who they deemed to be worse than them supported the role that they were trying to establish for themselves. For example, during the patient focus group Robert discussed how he always tries to find people worse off than him

Robert: I always try and look at other people worse off with me

Catherine: well yes yes

Robert: well I could have this you know, I could have had MS you know, like they don't get better do they, at least I've got hope, at least they said I could get better. Or should get better, but they've got nothing have they.

Catherine: yes, yes that's right, that's where positive thinking comes in

Robert: hmm, at least I can walk, you know things like that, I've got a lot to be grateful for really

Catherine: yes, me too

Robert: but that's what helps when you go along

(PFG: lines 685 – 694)

Both Robert and Catherine agree that seeing people "worse off" than them helps them to carry on and gives them an element of hope for the future. This suggests that they consider some conditions to be hopeless.

Sam (relative) has experienced feelings of homogenisation and categorisation of older people, particularly by politicians and the media. This sometimes made her feel like a drain on society, she compared herself to younger people who were claiming benefits and felt it unfair

Sam: well I think you're made to feel, I mean when you hear of some of the news things, you know "the elderly", you know I don't think of myself as elderly, they're a drain on because of all your like in (current town) there is perhaps a lot of older people, but we paid all those insurance and those taxes and touch wood my husband and I were never really out of work we changed our jobs but then all of a sudden we are a bit of a drain on and then you think, yeah you are perhaps feeling

Cathy: second class citizens

Sam: yeah and disregarded but because yes now we now need help and care unfortunately, but we have paid in its not they don't sort of say well that person, I left school at 15 and I started work and I paid in years and years and all of a sudden these elderly people they are a bit of a drain on the funding, but these young people.

Pete: they don't remember that they might be lucky enough to get to our age

Sam: you know an example, you know my father, well he was "don't you start going in there" well I had a couple of friends then , you know they perhaps went off to aunty and had the baby, but now, I want all my benefits now I'm a single mother and all that, and you think, this man here has paid all this things and then it goes, whereas they have babies and now I want a property and I want, I think that makes you feel, you know we're not a drain, we've paid in a lot

(RFG lines 323-340)

Sam and Cathy infer that their age and potential need for care makes them feel disregarded and less valued as others who are younger. Although overall the Day Hospital had a culture of inclusivity and apparent value for patients, there were times I observed discussions which may support Sam and Cathy's feelings. During the observation phase for example, I noted that there appeared to be more sorrowful feelings displayed by the staff towards younger patients using the service. Having spent time listening to the different staff interact with patients in the public areas and discussions within the office I started to develop an understanding of people's roles within the team.

There is a core member body within the staff, many of whom are older than the rotational staff and appear to have been at the Day Hospital for several years (some 20+ years). There are some students who are paired up with these therapists and nurses dependent on their discipline. These more senior staff carry out the initial assessments on patients at their first visit and develop their goals with them. These assessments referred to as '360 assessments' or '360s' are the initial assessment that all patients have when referred to the Day Hospital. The staff that are carrying out the assessments that day have an early morning meeting where they allocate the assessments based on the primary need of the patient and then tend to read their patient referrals before they see them. During this observation the physio was explaining the system to the student, she said that they look at the notes to "*get a picture of what is going on before we meet them*". I asked her if I could come into the assessment with her to which she agreed.

Assessment on 68-year-old woman (Jane pseudonym) who has rheumatoid arthritis, fibromyalgia and chronic fatigue syndrome. Before calling Jane in to the room the physio looks through Janes notes she says, "oh she's a young one, poor woman" I ask her how old she is she says 68, "that's young here, but she looks like she has had problems quite a while, quite a long history". The physio goes out to get Jane; they seem to take a while to get back to the room. Jane walks in, she is a short woman around 5 feet 1 or 2 with a slightly hunched back and walks with fisher stick crutches. She looks younger than her years as she has good skin and she is wearing quite unusual but what I would call fashionably funky clothes. She walks into the room with a slight limp, she acknowledged me with a nod and smile and sat down on the chair nearest the desk. The physio walked in behind her followed by a man. The man was wearing similar clothes to Jane in terms of style and had noticeably bright glasses on, he looked to be in his 50s, and he introduced himself as Jane's husband with a handshake. He took a seat next to Jane, the physio sat at the desk and turned her chair to the couple, and I sat behind her slightly on the bed. The physio began to explain what the assessment would entail; Jane sat listening intently with a slight frown on her face yet nodding as the physio spoke. The physio explained that she would be looking at all aspects of Janes life in order to get a full picture so she could best help her. Jane said she had brought her husband along to help as she forgets things a lot and gets "brain fog", they both laughed at this.*

After most of the assessment had finished the physio left the room to book Jane's next appointment and Jane began to speak to me. She said that she feels so old now and hates her "stupid body". She said, "I was young like you once, don't take it for granted". She smiled as she said it, but she seemed sad and wistful. I told her that I liked her top and shoes. She said that she was a designer and had a different style that not everyone likes. I told her that I would like to wear things like that, but I don't feel bold enough. She said, "you should, you have nothing to lose". The physio returned and gave her the appointment and showed her out to the waiting room. When she came back she again commented something along the lines of poor woman and said, "we want to try and see Jane as the whole person not just the person with pain or falls".

(Taken from fieldnotes 15th December 2017)

During the assessment there was a real sense of pity from the physio towards the patient due to her condition but also, I felt linked to her age. Even before we met the patient the physio's tone of voice seemed tinged with sadness that the patient was experiencing these difficulties and there were several references to her age. I recognised that through her words and tone of voice I was building up a picture of what the person would be like and started to feel sorry for her myself, effectively through the description of a third party. I wondered what the effect of that type of description would be having on others for example students and rotational staff moving through the unit. It was not patronising or paternalistic, the underlining sense was compassion, but the sorrow that was felt somehow made me feel that the patient wasn't going to be able to improve or that her potential was perhaps lesser. I wondered if these thought processes limit the ability of the therapists/nurses to support the patient's past boundaries or if they become self-fulfilling prophesy. If the staff feel sorrowful for the patients does that then make them feel restricted in their abilities.

It was also apparent that the attribution of roles and identities assumed by staff regarding patients differed between clinical professional staff and those who were non-clinical or assistants. All staff appeared to contribute toward creating a positive environment for patients, however non-clinical staff, and sometimes the assistants, only had access to more visual cues, such as a patient's appearance, to determine how frail someone was. During the staff focus group for example Angela and Greg both in these later groups, discussed how they determine self-neglect in patients. Although they acknowledge that their views are not limited purely to older people, they use visual cues to develop their opinions.

Angela: yes, yes I think like Bethany said, it comes with age and very easily on the face you can recognise that they are vulnerable and weak very often you can say straight away that they live on their own if you observe

Moderator: what sort of things would give you that idea?

Angela: face expression, the eyes, the way they look at you, the way they say things to you, erm, the way how sometimes they can't manage themselves around with a walking stick and a handbag

Greg: it's also the way they dress

Angela: the way they dress, erm, you're right Greg sometimes they come in with lots of marks, after breakfast and eating

Greg: if somebody is old and got a partner, they make sure, especially if it's a man with a wife, she wants to make sure he's tidy

Angela: yes

Greg: before he goes out you know, if somebody's living on their own, not eating properly not washing their clothes properly you , going back in my experience with A&E you get people coming in through the door and you categorise them by how they act and how they dress, so if they haven't washed or dressed or brushed their hair it sticks out, it doesn't mean that their issues are any different in life or home, but you think perhaps that person needs a cup of tea, he needs warming because you see how they come in, and it can be any age from 18 – 108 it's just looking and thinking oh.

(SFG lines 26-45)

Nina, Laura and Bethany, all clinical professionals, responded to this with much broader perspectives

Nina: I must admit my tolerance to that sort of thing is a bit higher because I think you know as clinicians we all sort of turn ourselves out quite well, and I don't think everyone really cares about, with respect Greg, I don't think everyone really cares if they haven't shaved their legs or brushed their hair or, so I have a kind of higher threshold for that sort of thing. If someone is odorous I kind of, that will make me think actually you haven't washed for some time, or dirty shoes, if someone's shoes are absolutely filthy you know they are living a poor environment.

Laura: I think sometimes there is a difference, sometimes people chose to be like that, so if they come in a bit unkempt perhaps I wouldn't necessarily think oh they're frail, you know, there is a bit of a difference I think in a way rather than just looking at them you know when someone's what I deem frail when you work with them a bit more, and get to know them even just a little bit.

Bethany: I think it's how you look at the word as well, like there's frail and frailty, so if you look up frail in the dictionary it's not going to give you what frailty means, so if you look at someone and think they're frail you could be looking at the dictionary definition *of their weak you know that side of things and they are frail just like a piece of wood can be frail but frailty is almost like a different subject isn't it.* *(SFG lines 46-62)*

The clinical staff acknowledged that some patients may come in looking unkempt however they do not base their assessment of people on this, recognising that people live in different environments and may chose different lifestyles, but this doesn't define their frailty. They spend more time with them, assessing them as individuals before they may make that judgement.

The relatives reported an impact on their own identities. The role of carers featured heavily in both the observations and the focus group discussions. Several patients came with relatives/carers and during the focus groups the impact of taking on the role as a carer was discussed at length. Out of all the groups, this was the one that I found most difficult to moderate as there was a strong sense that everyone needed to share their individual story. I felt that this highlighted the isolation and loss of identity that many carers were feeling and certainly described during the discussion. Most relatives were spouses, but one focus group participant was a daughter who had moved in with her father after her mother's death. Here she describes how she feels she has lost her identity in her caring role.

Betty: Oh yes, I used to have a job abroad and then my mother died, both my mother and father were expected to die, well my father was expected to die but he survived and erm I think he feels a lot of irritation because I can't do household things the way he could and I'm still, because I worked abroad for many years I took a long time to get used to living in Britain again, and I still haven't passed my driving test and it's just, I kind of left behind a lot of decoration and stuff, a friend I used to work with a bit in University she saw me this summer and she said where are your rings, and she remembered I used to wear quite a few rings and I just haven't got time for that now and erm a relative rang up, it was my father's birthday two days ago and he, he's 92, and the relative said, are you doing any work. The temptation is to say, do you actually know what a carer does, you know even though you have to keep reminding yourself it's like a totally isolated existence, hived off from the rest of society unless you make the links, so nobody really knows how hard work it is except other carers and I just count myself lucky in that I'm able to do a bit of examining in the summer because I can do the marking at home, and I am teaching some Turkish people I met at the

> *hairdressers, they are the hairdresser actually so I can continue teaching them English, although it's not academic English which is what I did for five years before this, and I get a bit frustrated with myself because I can't, there a lot of, actually cooking is a big issue, my father has got lots wrong with his stomach and I've never cooked so much in my life and its mainly because he is putting up these things about he can't cope with readymade meals, he doesn't like anything recycled, so sometimes I see myself as, my image of myself now is a sort of like cook and bottle washer, rather than, and in fact instead of saying I'm a carer I want to say I'm a cook and bottle washer in a way because that's what I feel.* *(RFG lines 143-165)*

Betty's description of the changes in her identity since adopting the role of carer were very profound. She was an academic, and although she can do some University work at times, it was clear that others around her see her as 'not working'. Not only does Betty describe changes in her social status but also physical appearance, she feels that she doesn't have time to look after herself as she did previously, and this has amalgamated in her new self-given identity of "*cook and bottle washer*".

For both patients and relatives' changes in life roles can be significant and difficult to adapt to. Some older people feel that society casts a role upon them that renders them less valid than younger people. Some older people will personally challenge these felt stereotypes by portraying versions of themselves to others in order to re-establish their role. Others use social comparison to find others who they deem frailer than themselves which appears to improve their self-worth. Carers may feel that their role is undervalued and adopting this role has significant impacts on their identity and their relationships.

9.2 Interprofessional working – breaking down the barriers

Throughout the observations there was a feeling the staff really recognised the potential stressors and experiences that patients had already faced. Many of the staff, particularly the rotational ones, had worked on the acute wards within the hospital and throughout the staff focus group made reference to comparisons between these wards and the Day Hospital. In particular they felt that their integrated working practices across nursing and therapies supported a different culture of care in the Day Hospital.

Laura: I think it's not (referring to the wards) nearly so MDTish as we are here, I must say I've worked on loads of the wards at the hospital and often you don't even know the nurses names even if you're working there for months at a time, and I try and be quite friendly and I say hello

Nina: yeah you're really friendly

Laura: but you just sort of get quite negative, short responses and so quite quickly, even though I'm quite a positive person, you think oh well I guess I won't really bother then. You know and it's a real divide in a lot of people

Cross talk

Bethany: that's culture isn't it,

Hannah: it's cultural

Laura: it's a bit of culture, like here what I love is that the nurses, we are really integrated with nurses and on loads of wards there's a massive barrier between therapists and nurses, and I don't really know why, it's just a cultural thing so we just clash, not individuals but our approaches just don't seem to get on so we, but here were really together and I think that really helps the patients.

Angela: I used to go to the wards, and I could stand in the middle and they pass me by, they won't notice me often, no one even asked me what I'm doing here, but I stood there observing why they are doing this and the patients are not even noticed there and everyone is running so busy, but when I started to listen to them they were so busy it was unbelievable. The clerk, receptionist, two doctors actually in such a deep discussion about one patient trying to work out the best way they can release him from the pain it's unbelievable, so I'm there thinking, they're are not a bad, they try and do their best but they are so busy, bells ringing, they do, no one smiles there.

Bethany; I think it's too easy to say its busy, having worked on the wards, yeah you are busy but I think it's just become the thing, we're busy so were allowed to be stressed and a bit rude to everyone and actually it doesn't have to be like that and I don't think it is that busy, having worked on the wards, it is busy but you can cope.

Nina: I've found there's a culture as Hannah said, but I've found there is also a sub culture, so I found that there are people across the board, housekeepers blah blah, everybody who wanted to do right, who wanted to smile, wanted to be kind, and that's *there, it's there but it's a sub culture it's not the predominant way of being, but it is there and I think people do want that.* *(SFG lines 484-515)*

Laura's description of her experiences on the wards highlighted how a culture of negative interactions can quickly shut someone down. If we relate that to the experiences I have highlighted of some of the older people's interactions with health professionals, we can see how this may also contribute to their world closing down. The staff at the Day Hospital feel that they create a more integrated culture, they merge inter professional barriers, communicate and plan, and appear to respect and be open to learning from one another. This was witnessed during the observations particularly within the therapy office where I regularly overheard informal conversations regarding patients

Discussion with OT, nurse and therapy assistant.

Discussing a patient's cognition and memory and concerned that it is not as good as she reports.

She is the main carer for her husband, but she said she felt that she had just had a bad day when she first saw the OT. The OT felt that she didn't want to push for the ACE-R as she feels this might put her off seeing the OT. They discussed it and agreed that she would try this week and discuss the situation again with the patient.

The rehab assistant said that the woman and her husband adore each other but that he is 'old school' and doesn't really like her looking after him he wants to look after her.

(Taken from field notes 30th January 2018)

This informal conversation was being held regarding one of the patients who some of the staff had concerns about. The woman had been referred by her GP as she had had a fall and had lost confidence; she was also the main carer to her husband who had been diagnosed with dementia the year prior. The team seeing her felt that her cognition was much worse than she portrayed to the staff and that she was avoiding engaging in certain assessments to try and cover this fact. During the conversation there appeared to be a genuine concern for the patient and her husband, there was a sense that the staff were conscious to find the right way to approach the situation as they wanted to ensure that she wouldn't disengage if she felt that they were questioning her cognition. The conversation was very patient focused and explored several options for both the patient and her husband along with potential outcomes of the tests that could be completed. The group were considering ways to support the patient in a positive way, not to undermine her identity as her husband's carer or worry her that there was perhaps question about her ability to carry these duties out. There was an air of caution surrounding the relationship between the husband and wife and appreciation for the work that she was doing caring for her husband, especially as the team felt that her cognition was impaired. There was also concern for the husband that because of this, perhaps some of his needs may not have been fully met. Although it was the OT who raised the initial concern and it was her 'role' to assess and treat cognition, the group decided that the nurse should take the lead as they collectively felt she had a better connection with the couple. This was an example where the traditional roles of the disciplines were integrated for the benefit of the patient. The staff were insightful about the patient and relatives needs and the focus was on how they could best be supported rather than whose individual job it was to do it, it was considered a joint role of the team.

The closeness of the team was evident from an early stage in the observations, as highlighted previously colleagues would regularly hug each other and everyone seemed to be warmly greeted in the morning. There was a real sense of camaraderie within the room. At the start of the day there was often a little huddle of nurses and therapists planning their time, one thing that was notable was the willingness to support each other's work load, I will talk more about this later in this section, but this was facilitated because of the ability of staff to respectfully cross professional boundaries between disciplines and without retribution. During the focus group this was referred to as an ethos of positivity and it was highlighted that the closeness of the team was important in terms of the effectiveness of the patient experience.

Laura: I mean the ethos here is very positive, I think it's geared to helping people

Hannah: I think with such a close knit team we all work; I think it is multidisciplinary team working at its best

Nina: yeah I do

Hannah: and I think we all, every single one of us in all of our areas, we work so closely together, and we are such a happy team and I think that feeds out to the patients

Greg: yeah absolutely

Hannah: it's so important, and I think they pick up on that

(SFG lines 301-308)

Hannah (nurse) felt that the team's unity was recognised by the patients. This was also corroborated by patients reports of effective communication across team members, patients felt like the staff knew what they were doing. This created an environment of trust and appeared to make the patents and relatives feel valued and listened to. Nina (OT) describes this process within the office

Nina: well we are so close to each other, we're all in one office, we work

Bethany: sitting on top of each other

everyone laughs

Nina: you know one person finishes with a patient they hand the file to the next person, there's that little interaction isn't there, and we get to know how people are, because we drill down with our patients, we probably drill down with ourselves and maybe with each other to maybe what makes us human.

(SFG lines 335-341)

By looking to see which individuals are allocated to treat each patient, the staff know who to communicate with directly to discuss therapy, thus keeping the flow of patient information smooth and accurate. It reminded me of a relay team passing the baton between team members, where all are needed to play their part for the team to win. Members of staff refer to themselves as working well as a multidisciplinary team, but the Day Hospital approach is one of more interdisciplinary working where each of the disciplines coalesce with common goals rather than separate goals related to their discipline and integrated intervention (O'Daniel and Rosenstein 2008).

9.3 Colleague compassion and kindness

If we were to ask people what basic principles people need to hold to work in healthcare I am sure that compassion would be one. Indeed, many core values of contemporary hospitals include an element of providing compassionate care (NHS England 2014). We know however that older people, in particular, often experience poor levels of compassionate care in healthcare settings (Francis 2013; Bramley and Matiti 2014) (NHS England 2014). I have grouped together these words of compassion and kindness as ‘kindness’ was the term that both patients and staff used to describe each other, and kindness is certainly what I observed. As a working healthcare environment, I have described how the Day Hospital embodies positive practices for older people with frailty. This happens by creating a welcoming and therapeutic physical environment, as well as providing hospitability and an individualised patient experience. In addition to these a notable observation was how kind and compassionate staff and volunteers were to patients but also to each other.

I observed colleagues being compassionate towards each other and share moments of kindness on several occasions over the months. During the focus groups the staff acknowledged this caring culture towards each other, describing a positive ethos within the unit.

Nina: do you know yesterday I actually had a really difficult day, erm, (Nina became tearful). But I’m having a good day today (said in a happy voice) everyone laughed. So as Bethany said the time constraints are a genuine issue, you see that patient but that’s not the end of the story, you’ve got huge amounts of paperwork, you’ve got social services referral, you’ve got this that and the other, need to speak to him need to go there, and you’ve got this huge amount of work generated, it’s not just patient contact. So yesterday I had a tough day and this morning when I was driving in to work, I wasn’t even thinking about this I have to say at that moment, but do you know I think there was something that struck me that yesterday everyone, the staff were so kind to me. Everyone was kind, even though I was being a stress head and running around and just being not my normal self I suppose, everyone was really kind and I thought to myself, you know management was kind and I think that’s really important I think (the manager) is really fair, she is really kind, she sets the scene for us, she is a good role model and we’re all very kind to each other and the patients, yeah we’re kind to the *patients obviously but everyone was kind to me, and this morning I went in and just thought it's alright, I've got this, I can do this and I think without that kindness possibly I wouldn't have felt that way this morning, and I'd have come in, you've got all the stresses but then if you don't feel supported then that just, I've had it in other environments, you have the stresses but you don't have the support and its harder to get back on you're A game* *(SFG lines 301-327)*

Nina spoke about how the kindness shown by her colleagues as well as the management enabled her to feel supported and overcome the problems she was facing at that time. One thing that struck me during the observations was the openness of colleagues with each other, it always felt very human. People did not seem afraid to share their thoughts and feelings both work related and personal and people seemed to genuinely want to listen. Personally, I come from a very small family, but it felt like how I would imagine a family at Christmas time, everyone relaxed, helping each other, busy but laughing. People share times that they may have made a mistake or forgotten something without fear of retribution but seemingly knowing that they will find support. During the focus group they discussed how happy they are to share things with each other and how other environments can leave a negative impact for the patients.

Bethany: yeah I mean you can talk about anything in that office.

Hannah: and we do

everyone laughs loudly

Bethany: but you can though there is probably nothing in my life that I wouldn't share with a lot of you, and you want to hear it all. And that makes us close doesn't it you know, like I'm more than happy to share all my personal stuff and that helps because then we are that close

Sandy: one of my neighbours has just been an inpatient in the main hospital for three weeks and he's only young in his 50s , and he said that he felt the wards were bitchy, he could see nurses being horrible to other therapists, he said that they just didn't seem to work together. Whereas here I just don't think there's any bitchiness, I don't hear anyone talking about anyone, and I think we all get on well, were lucky we seem to get nice people that work here and I think that definitely makes a difference to the *patients how we all are and how we come across because that gave him like a negative affect during his stay*

Bethany: it does definitely have an effect yeah

(SFG lines 342-356)

Staff do not have to leave their personal lives at home, there appears to be a belief system where people are accepted as a whole, staff view each other as whole beings and because of this feel safe to share intimacies of their lives that are troubling them. The support offered is evident. On many occasions I witnessed staff covering patients for each other if they were feeling overwhelmed. Even without asking, there felt to be such an understanding of each other's personalities that people would approach others to check they were ok if they were particularly quiet or more reserved than usual. Humour was used often as a way to alleviate stress within the group. One example was when a nurse was evidently tearful in the office, people were comforting her, stroking her back and talking to her, someone made her a cup of tea. She wrote on an A4 sheet *"No one be kind to Olivia today she will cry".* Everyone had a chuckle. The next day I came in and someone had crossed out the name Olivia and written another name. It really made others laugh but I could also see this person was emotional and was using this as a form of humour to manage this. This way of being within the group felt very human, there was a sense of a shared journey, an integrated partnership that didn't reduce a person to their profession, a nurse, but viewed them as a whole person.

Nina (OT) discussed how personal some of the assessments are, she highlighted how the depth of questioning can make the patient feel very vulnerable as it brings their issues to the forefront before strangers. By adopting a humanised culture, the staff cannot act in a reductionist way, reducing the patient to their condition or compliant, instead the patients are viewed with a wholeness, recognition of the person within the patient presenting at the Day Hospital.

9.4 Sense of community spirit

The closeness of the team and the support they offer each other creates a sense of camaraderie and community within the unit. This feeling of community is forged in the actions discussed in the previous section where therapeutic relationships are valued and developed and all who work and access the unit contribute to a shared experience. During the observations many patients spoke about how isolated they had felt at home at times and that attending the Day Hospital enabled them to recognise they were not experiencing these problems alone. During the patient focus group Adam discussed how he felt meeting others in the same position

Adam: I think you think you're the only one laying in the garden when you can't get up. But you come here any everyone's the same

(PFG lines 683-684)

Catherine also spoke of her loneliness since her husband died and the added social benefits of attending the unit.

Catherine: when you're on your own living at home and you're looking at the same four walls, ok you get out as much as you can but it's nice to come out and see four different walls and to see people, it's really nice.

(PFG lines 62-64)

The importance of social engagement in motivation and well-being is well documented (Mendes de Leon 2005; Park 2009). Linked to the loses described in the first section of this chapter, many of the volunteers, themselves bereaved, recognise the social culture within the Day Hospital and the benefit to them as individuals.

Bernie: well when you're widowed it's another day to focus on

Amy: when you're on your own it's nice to get out and about and chat to people and its ideal here.

Bernie: I do two other voluntary jobs as well as this, (Bernie explains the 2 charities she volunteers for). *(VFG lines 113 – 117)*

The Day Hospital also creates opportunities for these social engagements by holding seasonal events. During holiday periods such as Easter and Christmas the Day Hospital decorate the unit and create a feeling of celebration, for example during the lead up to Christmas mince pies and Irish cream liqueur was available for patients whilst they are waiting.

Figure 23: Mince pies and baileys

The Day Hospital not only decorates the unit and provide gifts for the staff and volunteers but also organises a Christmas tea dance where they invite all patients, relatives and volunteers who have attended that year. I discovered that the tea dance had become an annual event, a band is invited in to play music, there is dancing, and food is provided. The staff appeared to get excited about the dance in November when many conversations were held about inviting patients and roles on the day. Patients were given a postcard invitation which was individually addressed to them and often looked surprised that such an event was happening in a hospital. The buzz leading up to the dance made it feel attractive, having listened to the planning I personally started to feel excited for the day.

On the day of the tea dance many more staff arrived at the unit than were on duty, some brought their children with them and there was lots of hustle and bustle getting things prepared. There was buffet food and drinks that needed to be prepared which the staff did rather than the volunteers. In the corner a band set up instruments, there was a guitarist a drummer and a keyboard player and an area is left in front of them as a dance floor. They practice before most people arrive and some of the staff start to dance with each other and swing each other around on the dance floor laughing. It is much noisier than usual and this level of chatting and laughing creates a very different feel to the environment, it feels disassociated from healthcare in any way really, this is also due to the Christmas decorations which have been put up around the rooms.

As people arrive to the dance the staff stand in a kind of line along the side of the wall and great people as they come in, many by name, some they hug or walk to a seat. I couldn’t work out if the line was intentionally structured or if they just found themselves like that, but most get involved with welcoming the patients whether they were on duty or not.

Many of the patients appeared to have ‘dressed up’ for the occasion. The staff passed lots of comments about how lovely they looked and how they had dressed up. Most of the men wore a suit and tie and the women dresses and hats. The staff all had Christmas themed adornments to their uniforms either, hats, or earring or broaches, and those that weren’t on duty wore Christmas outfits. Everything felt different to a normal day, the staff were expressing themselves through the adornments of their uniforms and the singing and dancing, the patients were expressing themselves in a different way by dressing up and showing different sides to their character than in the patients/health professional relationship that they had previously had. One couple were highly discussed by the staff as they were dancing closely together and he had his hand on her bottom, many of the staff passed comment on it with lots of smiling and some mild embarrassment. The amount of talk around this couple highlighted to me that although the staff appeared very good at encompassing the whole person in to their treatment, they perhaps had not previously viewed them as sexual beings, on reflection I never encountered any discussion regarding sexual relationships within the unit. Fascinatingly none of the patients or visitors seemed interested in the couple or surprised at their closeness, perhaps indicating that this closeness was accepted as normal for those in this age range.

Many of the patients that were sat down were singing along to the music or tapping their feet/hands. The staff went around with trays with canapés on and offered the patients/ relatives food and drink. There was a real sense of community, the staff looked for people who are sat on their own and tried to get them up on the dance floor, some stayed standing where they were and swayed side to side with the support of the staff member. It felt supportive; the staff seemed to want to support the patients in their engagement and enjoyment in the music and the dancing if possible. The staff were very complimentary to the patients about how they looked, and the effort they made in to getting ready. I offered to take some of the food around and hand it out. The food has been donated by Waitrose and was of high quality and different to the food they are given at the day hospital. The patients comment on it saying how tasty it is. One woman stopped me and asked if I made the food, I explained it had been donated. She said, “it’s very nice, I haven’t been out to eat in years it tastes like posh food” and laughed.

A couple were sat on a table toward the back of the area. There was some space, so I sat down beside them and asked them what they thought of the event. They said they felt it was a great idea, they had never seen anything like that before in a hospital and is good for “the old people like us”. I asked them why that was? Did they feel like there wasn’t much for them? They said

“I think there’s a lot that goes on now days for the old folk. It’s always in the news about dementia and being lonely and things. But it’s only if someone really tells you to come along that you feel like going. I wouldn’t have thought many people would just go along without being invited, they invited us here”

(Taken from fieldnotes 21st December 2017)

This was one of the first and few times that I heard someone refer to themselves as old. The thought that being invited personally felt important to them and encouraged them to attend, seemed to corroborate the volunteers’ concept of increased passivity with age, during the focus groups they discussed that older people needed encouragement to do things on several occasions

Gemma: but that age group they want someone to come in there and say this is what's happening you're going, but they don't, because no one will go and say this is what's happening you're going.

Sarah: and this is why I think this is what we need here, we need more people to say did you know that you could go there

Gemma: go give it a try

Sarah: but then they don't do it, so as you said you need somebody who will literally go there and say right, on Tuesday *(VFG lines 235 – 242)*

This is interesting because they are of the same age group but I sense that if someone told the volunteers that they had to do something they probably wouldn't like to be told that, so it must be something other than age that is defining this impression for them. Overall, the volunteer group were more vocal about the need for someone else to take control of what the patients did as they didn't think they actually do the thigs they say they would.

Either way, the warm personal invitation and welcome they received created a sense of value and that they were wanted there. People were encouraged to be actively part of the community of the unit, the community was something that was shared. People could be part of something, this shared experience of frailty and ageing, this shared experience of strength to overcome their fears and rebalance their lives. The camaraderie rallies the troops to push forward, but forward in a space where there is mutual understanding that forward, backwards, sideways, up and down are all accept parts of the human journey of ageing with frailty.

9.5 Frailty experienced as Ontological insecurity - Making sense of a changing world

Overall, the findings suggest that the condition of frailty challenges numerous aspects of a person's life including their sense of self-identity. Frailty brings with it insecurity and imbalance, both in the physical and metaphorical sense. For the older person with frailty and their relatives, their world as they know it changes. It becomes an unpredictable and insecure place which requires older people to constantly work at rebalancing their lives to re-establish secure footings within their worlds. When reflecting upon these findings and previous understandings of how frailty is socially perceived I came to visualise the frailty journey as being comparable to walking a tightrope. The tightrope is made up of strands of fibre; each fibre is an element of our lives, our partners, friendships, work, health and so on. For many in adulthood their tightrope is secure, wide and stable, their strands are fulsome and gathered. Of course, we all experience episodes in our lives where security and stability may fluctuate however, many younger people retain the intrinsic capacity to overcome this instability and re-secure themselves on their tightrope. Their life stands remain intact and full. As we age many of us begin to experience losses; we may experience close bereavements, our friendships and social circles may diminish, our life strands start to fray, and as strands of our life are lost our tightrope becomes narrower. This narrowing requires greater balance, people must work harder to remain balanced, stable and feel secure. The arrival of frailty challenges this security further. Additional life strand losses of functionality, postural stability and cognitive functioning further narrow the rope. With each insult to the life strand the intrinsic capacity to recover is lowered, older people with frailty can often see their rope narrowing and fear begins to build with the anticipation of further losses. Adaptation is needed, but difficult to manage. Some may begin to walk their tightrope more slowly in the hopes that it remains more stable, some may begin to crawl along their rope, in the hope of feeling greater security. At this stage however, others in society, observing the older persons slowness or crawl may start to construct perceptions regarding their capabilities. Interventions may begin to occur; a fall may lead to a hospital admission, involvement of family or health professionals looking to support the older person may lead to carers being introduced, routines may be changed, and choices may be limited. The findings suggest that older people experiencing these types of interventions may begin to feel more helpless, their identities become blurred. The experience of frailty can feel medicalised and focus on the losses experienced may distract from the capabilities of the individual.

The older person may have felt unbalanced, but they were working hard to remain balanced, if this is not recognised and appreciated then the skills and capacities that they used to maintain this balance may be ignored and engagement in services can be rejected by an individual. The processes and created culture identified in these findings support older people to re-secure themselves. A pictorial representation can be seen in Figure 24 below.

‘*Walking a frailty tightrope’*

Figure 24: Frailty tightrope

9.5.1 Explanation of the stages of the frailty tightrope

At the start of the image we see a man, I will name him John. John is 83 years old and lives with his wife in a three bedroom house. They have one daughter who lives in a different part of the country but speaks to them regularly on the phone. John is a retired electrician; he and his wife regularly attend church and have several friends that they meet for coffee or lunch. John has noticed that he has slowed up in recent months, he still drives and manages his garden but is finding things a bit harder. In the first image we see John balancing on his life tightrope. At this point the tightrope is still quite thick and supportive, the strands of the rope remain connected and full.

As time progresses however, some of the strands begin to unravel from the rope, John’s wife dies suddenly. Her death came as a shock to everyone and John understandably feels low and isolated. As the weeks and months pass after her death many of the social circles he engaged in with his wife feel as though they are a distant memory. Johns routines have changed, his wife cooked all the meals previously and John is finding learning to cook challenging and is surviving on ready meals. As time progresses John finds that his social circles close even further. He is reluctant to go out on his own and is spending more time in the house, he has stopped going to church, and many of his friends have stopped calling or popping in. Over time he notices that his legs do not feel as strong as they did before and, although he hasn’t fallen over, he feels unbalanced and starts to use the furniture in his house to keep him steady when walking around. John’s daughter lives about 200miles away but calls him regularly, he mentions to her that he feels a bit unsteady, so she orders him a walking stick from the internet.

As time passes John’s life tightrope gradually becomes thinner, he has now experienced several falls within the house and garden, but he hasn’t told his daughter as he doesn’t want to worry her. He chooses instead to stop going out in the garden. He is struggling to get his shopping and quite often goes without a hot meal. He is also feeling much lonelier, he doesn’t speak to people often and feels as though he is becoming trapped in his house, the world outside feels distant and his world inside is closing around him. John experiences greyness in his life (represented by the background colour), he feels that everything is becoming harder for him and he is frustrated about this. He decides to try and do some gardening to cheer himself up, he is fearful of going outside now but wants to ‘get back to normal.’ Unfortunately, John loses his balance in the garden and has a fall. This time he is unable to get up on his own and he lies there for what feels like hours shouting until his neighbour hears him and calls an ambulance. John feels embarrassed, he doesn’t want to go to hospital, but the paramedics feel it would be wise as he was on the floor for so long. In hospital he is assessed by a frailty team who agree he can return home but would like him to attend a Day Hospital for some rehabilitation. John is reluctant but agrees, partly because he feels that is the only way they will let him go home.

In the third image we see John entering the Day Hospital. At this point his tightrope has become very thin, and we can see life strands fraying away beneath his feet. It is harder for him to keep balanced both physically and metaphorically and he has slowed down considerably, as he creeps into the Day Hospital. The Day Hospital building (represented under the tightrope) provides stability for John’s fraying tightrope. He now feels very weak and is falling quite regularly, he has lost weight and his memory is not as good as it used to be. John feels unsure about attending the Day Hospital, but when he arrives he is welcomed by the receptionist and offered a cup of tea and some lunch by the volunteers. John is delighted to have this as he hasn’t had a cup of tea made for him in some time. As he waits in the waiting area the man next to him strikes up conversation. He too has lost his wife and they talk about how their houses and gardens. John begins to feel more relaxed, as the weeks pass he starts to develop friendships with the other patients who attend at the same time as him and some of the staff.

In image four we see John started to become more balanced. Physically his falls have reduced at home, his legs have become stronger and he feels more confident walking around his house and garden. The staff at the Day Hospital (represented by the staff member and safety net) have helped John set up a call bell system at home and arranged hot meals to be delivered for him. They have also put John in touch with some local groups who meet for coffee in a church hall near to where he lives. John begins to feel less isolated; he employs the help of a cleaner and gardener, and when they are at the house John feels more secure to go out and do his potting that he used to love. At the social group he has made some new friends, he realises that there are others in a similar position to himself and takes some comfort and strength in this as his life strands begin to slowly rebuild.

In the final image we see John walking away from the Day Hospital as he finishes his period of rehabilitation. Although Johns tightrope is not as full as it was a few years ago at the start of his frailty journey, it feels more stable to him, his world has started to open up again and become brighter. Life is still sometimes hard, he is slower than he used to be, but the staff at the Day Hospital have empowered him with tools to pace himself through his daily activities. He enjoyed his time there but knows that he can go back if things become hard for him again. There is a new sense of security, John’s mood improves, and he is enabled to live what he considered to be a more fulfilled and ‘normal’ life once more.

Chapter 10 Discussion: Walking the frailty tightrope – ontological insecurity

"The body is an object in which we are all privileged, or doomed, to dwell, the source of feelings of well-being and pleasure, but also the site of illnesses and strains…It is an action-system, a mode of praxis, and its practical immersion in the interactions of day-to-day life is an essential part of the sustaining of a coherent sense of self-identity."

(Giddens 1991, pg. 99)

10.1 Chapter introduction

The previous chapters documented the findings from this ethnographic study which suggest that sense of self-identity in older people with frailty is often diminished through multiple losses, changes in social roles and societal perceptions of frailty. Living with frailty, positions people in an unpredictable world where they strive to balance numerous aspects of their lives both practically, psychologically and metaphorically. I have suggested that because of this, frailty can be experienced as ontological insecurity, this may be because a person's sense of order and continuity in their world is disrupted or that they develop negatives views of themselves and their world (Giddens 1991). I visually represented the findings as '***Walking a frailty tightrope'***, where the tightrope is constructed by strands of our lifeworld, as these strands 'fray' or diminish within the condition of frailty, the tightrope becomes weaker and more unstable and the 'footings' of the life journey become harder to navigate. Nevertheless, the findings also suggest that sense of self-identity can be positively constructed, and ontological security re-established through the environment, processes, interactions and connections made within the Day Hospital. This chapter discusses these findings and summaries the contribution of this work to the small body of current knowledge regarding the identities of older people with frailty, particularly within a healthcare setting. Strengths and limitations of the study will be outlined, and implications of these findings with regards to both clinical practice and future research will be explored.

10.2 Summary of research and contribution to knowledge

In this study I set out to understand how sense of self-identity in older people with frailty was experienced, understood and enacted within an NHS Day Hospital. I looked to understand the discursive and behavioural processes which contributed to the construction of these identities; which processes need to be in place to support a positive sense of self-identity, and how this may relate to engagement in services. An ethnographic approach was used to conduct the study over a 17-month data collection period, combining observations, participant observations, informal interviews and focus group methods.

As far as I am aware this is the first study to ethnographically explore the construction of identity in older people with frailty within an NHS setting. The findings of the study contribute knowledge in three main areas firstly; that sense of self-identity in people with frailty is constructed through numerous losses and social perceptions that shape their social roles. This can create a sense of ontological insecurity, or disruption to the order of their lives as they know them.

Secondly humanising processes within the Day Hospital, supported people with frailty to feel more secure in their daily activities, social roles and identities. This was achieved through fostering a hospitable environment and building a culture of humanising relationships on embodied relational knowledge. These cultural processes contributed to older people with frailty engaging more fully in their rehabilitative journey.

Finally, the study revealed that the construction of a nurturing and accepting work culture, is an essential foundation to support humanising and embodied practice for older people with frailty.

I will now discuss where these findings sit within the wider body of frailty literature, and how they contribute new understandings of the construction of sense of self-identity in older people with frailty within a healthcare setting.

10.3 Constructs of identity in frailty - Balancing losses in frailty

The findings of this study suggest that the identities of older people with frailty are constructed, in part, by numerous losses experienced on a personal level, as well as societal perceptions of what it means to ‘be old and frail’. Older people entered the Day Hospital carrying these perceptions, often experienced as burdens and limitations. Multiple changes within the lives of older people with frailty gradually build up over time like sediment, forming new structures and meanings within their worlds. These changes appear to influence the social roles for the older person, and often their close relatives or carers. Changes are generally experienced or perceived to be negative, however, older people work hard to rebalance their sense of self-identity through negotiating risks, implementing routines and portraying independence (Nicholson et al. 2012, Skilbeck et al. 2018). Frailty was experienced as life becoming unpredictable and existentially insecure. As strands of their life appeared to diminish beneath their ‘footing’, such as their physical abilities; their social worlds often became smaller. This at times instigated further cycles of loss, as reduction in social activities due to reduced physical abilities, led to increased muscle loss, further reduction in physicality and more social isolation. Dichotomous periods were experienced where on one hand people expressed wanting to ‘feel like themselves again’, yet simultaneously they actively avoided outside health intervention as this was often associated with failure and decline, a finding which has been identified in other literature where older people resisted what they considered to be coercive acts of power, by declining external support, even though they recognised they found things hard (Grenier and Hanley 2007), or their bodies precarious and unreliable (Ellis-Hill et al. 2000). And through actively resisting a perceived ‘fixed’ identity of frailty (Age UK and British Geriatric Society 2015, Grenier and Hanley 2007, Warmoth 2016). Daily living became hard work, yet it was clear that older people with frailty held capabilities and resources which were keeping them balanced, if rather precariously, within their worlds.

These study findings suggest that older people entered the Day Hospital in a state of ontological insecurity, a state of disorder within their world (Giddens

1991). Chronological age was infrequently referred to, and functionality appeared to hold greater importance. Multiple losses were formed or worsened by the condition of frailty, and these challenged their existential sense of ‘being’ within their worlds. This sense of insecurity and imbalance in daily lives and routines, required additional personal resilience and capacity to manage. These findings are congruent with previous studies, that suggest the onset of a long term illness such as frailty brings with it such existential disruption to people’s lives (Nicholson et al. 2012; Berglund 2014; Warmoth et al. 2016; Skilbeck et al. 2018). Nicholson et al. (2012) contend that frailty in older people is experienced as a state of unbalance, that requires them to ‘hold together’ loss of connections, whilst sustaining others. The work undertaken of balancing, highlighted by Nicholson et al’s. (2012) was certainly supported by the findings of this study. Part of this balancing act was to implement rituals and routines which appeared to re-establish some security and control for the older person. The continual act of balancing and the feelings of precarity, fear and anxiety about the future, for some became exhausting, and sense of self-identity further diminished. Whitaker (2019) points out how anxiety and feelings of insecurity about our ‘being’ and thus our identity is synonymous with the understanding of the potential or certainty of our ‘non-being’. From this perspective, these findings suggest that the anxiety and fears that older people in this study experienced regarding their ‘existential being’, may in fact point to much deeper insight and consciousness of their life phase. A fear, such as ‘fear of falling’ runs much deeper than the physical consequence of the fall; anxieties regarding cognitive decline or loss of driving ability, appear to hold more existential profundity when viewed through Whitaker’s (2019) lens.

The fear and anxiety demonstrated and discussed in this study may be more to do with the inability for older people to predict what is going to happen, as their bodies and world as they knew it to be, is no longer predictable. Giddens (1991) discusses this concept in terms of practical consciousness, the knowledgeability that we bring to tasks in everyday life. If our knowledgeability is questioned i.e., we fall when we expect to stand, our ontological security (our sense of stability and order in life) diminishes. In Chapter 7, we see evidence that changes in functionality or sudden events and losses were commonly experienced as a shock. New things had to be learnt, new connections formed, most of which were generally unexpected, and experienced as challenging not only in a physical sense but also in terms of sense of self-identity. In response to losses and challenges to self, the findings suggest that older people worked hard to maintain a sense of self-identity and resisted being labelled as frail. This will be discussed in more detail below.

10.3.1 Maintaining sense of self-identity - Resisting the ‘frail identity’

This type of resistance to a ‘frail identity’ is in line with the findings of other frailty research (Warmoth et al. 2016; Nicholson et al. 2012; Nicholson 2017a; Archibald et al. 2020; Schoenborn 2018). In this study I suggest that ‘resistance’ was evidenced in several ways; some denied their illness and attempted to carry on as ‘usual’, however this strategy was often opposed by others in their social circles such as friends and family (see findings chapter 7.2). A second strategy was to employ social comparisons, where they compared themselves to others who they considered to be less fortunate or able than themselves (see findings chapter 7.5). This appeared to serve two purposes; firstly, it distanced them from the concept of frailty and the negative connotations this engendered, secondly by comparing themselves to others, they were highlighting areas and attributes of their lives that they considered to be comparably better, this generated feelings of hope. Finally, establishing rituals and routines was used as a way of reconstructing their lives, perhaps in an attenuated capacity, but with elements of their selves embedded.

Narratives of rituals and routines within the findings further substantiate their importance in the wider literature in terms of constructing feelings of stability for the identities of older people living with frailty. Skilbeck et al. (2018) highlights the maintenance of performing daily routines as an important coping strategy to manage episodes of ill health and continual symptoms of frailty such as fatigue. My study findings similarly highlighted the implementation of practical strategies such as washing their top half in the morning and the bottom half in the evening, as a way of managing fatigue and remaining presentable. Over the course of the study it became clear that the need to establish and maintain routines was not only important for symptom control but was also a strategy to stave off further perceived disruptions to their lives that may further challenge their sense of self-identity. These actions could be perceived not only as a way of managing their symptoms and activities of daily living, as previously suggested (Warmoth et al. 2016; Skilbeck et al. 2018), but also a way of rebuilding and restructuring a new practical consciousness, or knowledgeability about their changing world (Giddens 1991). From this perspective I suggest that the older people in this study were able to demonstrate significant internal reserve and practical consciousness. This view could also explain why certain disruptions, such as the need for carers or a hospital admission, were particularly feared, because they were potential threats to an already fragile sense of order and balance in a person’s life. Brenda’s fears, for example, surrounding the care of her dog and navigation of her way home on discharge from hospital, significantly influenced her actions in terms of accessing or avoiding external support. Brenda’s and others experience were that the Hospital ‘system’ did not recognise or prioritise these aspects of Brenda’s world which were important to her. Focus of care was medicalised; aspects of life outside the boundaries set up by the medical gaze, were negated. This resulted in the avoidance of intervention where possible, even when the potential ‘risks’ to health appeared high.

10.3.2 Maintaining sense of self – Negotiating risk and attributing meaning

For many older people in this study, the risk of social role loss, maintenance of sense of self-identity and feelings of stability, appeared to hold much greater importance than the potential of physical risks. The identification of frailty in others, was denoted, by older people, as a state of inability, lack of independence or choice, and not a label to be attached to one’s self. A person being unable to do things for themselves was a key determinant to ‘being frail’ and was a concept often linked to the period immediately prior to death. If frailty is associated with being unable to control both themselves and their environments, then it is likely that older people would seek to maintain this control, if only to preserve their non frail identity. There was a sense of finality associated with frailty, it was not a static position, as has been highlighted in other research (Archibald et al. 2020), yet paradoxically often seen as one where there is only one trajectory, once you were deemed to be frail then there was no return (Gilleard and Higgs 2010; Higgs and Gilleard 2014). People with frailty were the ‘others’ and there was a keenness to avoid becoming part of this group.

For people entering the Day Hospital, their previous experiences of health interventions suggested that the importance of the maintenance of sense of self- identity was not fully appreciated by health professionals, particularly when physical risks were perceived by health professionals or family to be high. If we think back to Adam and Robert in the patient focus group, there was clear objection from their wives regarding them undertaking certain activities due to perceived risk, yet they continued to do them, admittedly out of sight of their partners. Activities that were perceived as now ‘risky’, were often relatively mundane tasks that the older person had previously undertaken such as cutting the hedges or getting the Christmas decorations out of the loft. Again, this can be interpreted as a threat to the older person’s practical consciousness. For most, they could identify the potential of physical risk, yet these were often activities that they had carried out many times before. Similar findings were also identified in Ballinger’s and Payne’s (2002) study looking at construction of risk of falling in a Day Hospital. They found differentiation in focus between the staff (on physical risk reduction), and patients who were more concerned about the social risk to their identities and experienced interactions in which older people felt stereotyped and infantilised. Giddens (1991) suggests that when we plan our daily routine we take account of a ‘package’ or risks, rather than assessing the implications of individual risks. Applying this theory to those in this study, we can surmise that individual risks, that may be the focus for family or health professionals, are assessed by the older person amongst a larger ‘package’ of risk. This ‘package’ will be anchored on their knowledgeability of not only what they are physically capable of, but also what actions need to take place for them to maintain a sense of self-identity. This could explain why there were differentiations within the findings, between patients and their families/relatives regarding perceived risks, and how recognising that risks are negotiated and assessed within a larger context of a person’s social world is important. It further indicates that, in the wider context, there is a lack of appreciation of the importance of maintenance of self-identity in a healthcare setting.

The way in which older people attribute importance and negotiate risk in relation to strands of their lives could be explained as a way of them establishing meaning in their daily lives and would further support the concept of ontological insecurity. Skilbeck et al., (2018) describes the search for meaning within the lives of older people as the foundation to repairing felt disruptions. The concept of ‘meaning in life’ has been highly theorised and debated (Kinnier et al. 2003; Moore et al. 2006; Brandstätter et al. 2012; Steptoe and Fancourt 2019), the debates of which are outside the scope of this thesis however, the concept of meaning is relevant here to these findings. In chapter 3 I discussed the theory of symbolic interaction as a theoretical underpinning for this study. Within this theory our ideas, beliefs and meanings in life, are thought to be developed through, and symbolised by, social systems and the roles we adopt and enact within them (Blumer 2018). Through this lens, the findings of this study suggest that actions and roles played and portrayed by older people with frailty are based upon not only on their perception of the action undertaken, but also on the impression that they want to create to others, as they present their selves in everyday life (Grenier and Hanley 2007; Horder et al. 2013). All awhile, felt disruptions to their lives create a sense of ontological insecurity, where things became disordered and meanings change. Recently, Lloyd et al., (2019), in their study of life narratives of people with frailty, link these tensive presentations of self to societal perceptions of successful ageing and frailty, whereby one is expected to battle against certain illnesses such as cancer, yet graciously accept frailty as being part of old age.

The ageing body creates threats to sense of self-identity, as ability is socially associated with youth and value (Westerhof and Tulle 2007), and medical interventions focus on inabilities and deficits (Fried et al. 2001; Mitnitski et al. 2001; Rockwood et al. 2005). Subsequently older people with frailty may present themselves in certain ways in order to attribute more meaning and social value to their lives. The negotiation of risk and differential presentation of self, demonstrated within this study, could then be viewed not only as a way of maintaining a sense of self-identity and avoidance of being labelled as frail; but also as a resilient attribute and capability, a life skill that could be harnessed, developed and utilised in positive ways. The findings demonstrate that before any therapy input within the Day Hospital, older people with frailty hold beliefs regarding frailty and old age and have already employed different strategies to manage both their health challenges and their sense of self.

10.4 Day Hospital Processes

The findings highlight a number of processes which occurred within the Day Hospital, many of which appeared to create a more positive pathway for older people with frailty to begin to rebuild their sense of self affected by their losses, and in doing so constructed and ‘firmed’ up parts of their uncertain identities. These processes centred around the Day Hospital fostering a hospitable environment where older people and their relatives felt welcomed and cared for. Humanising connections (Todres et al. 2009) formed the basis of many interactions. There were many ways that people were supported to feel more ‘human’. There was a sense of shared journey and togetherness that supported feelings of security, emboldening people within a safe space to allow the potential of their worlds to reopen to new possibilities. The provision and sharing of food within the Day Hospital both amongst patients, relatives and staff created a sense of homeliness and socially familiar rituals within an unfamiliar environment. Individual capabilities, capacity and potential of the older person were seen, acknowledged and utilised as the foundations of their rehabilitation. Acknowledgment of loss but focus on capability appeared to reduce fear and increase hope. Patients and their relatives became more engaged in their rehabilitation as some of their losses, such as mobility, started to improve, various parts of their ‘life strands’ started to restore and their footing on their frailty tightrope became more secure. As confidence grew, connections were made and security felt, the identities of the older people with frailty were more positively constructed. There is not one process that held greater importance than others, rather it was the interweaving of these processes and contributing cultural practices that imbued positive therapeutic connections and outcomes. In this next section I interpret how the processes within, and milieu of the Day Hospital contributed to sense of self-identity for older people.

10.4.1 Fostering a hospitable environment.

Feelings of hospitality were strong within the unit and overall appeared to be unexpected by the patients, the data highlights that people entered the Day Hospital with preconceptions about what a hospital was, what would happen and how people behaved within one. These thoughts tended to be negative, many had experienced problems in previous health encounters such as lack of time and communication and this had come to be expected. These notions are reflected within the wider literature where older people express concerns regarding loss of control and power during within hospitals (Tauber-Gilmore et al. 2018), and loss of dignity (The Patient Association 2013). Additionally, these experiences were set within the context of older people resisting the need for outside intervention in order to maintain their identities as described in Chapter 7.3. These preconceptions regarding hospitals were not only held by patients but also by staff, as the physio Bethany recalled her previous experiences of a Day Hospital as being untherapeutic, too clinical and disjointed. She represented her previous hospital as a colour, grey, in comparison to the bright pinks and yellows that were in this Day Hospital. Bethany's description of how she perceived the Day Hospital was comparable to how patients discussed it during the observations, "Cheerful", "bright" and "lovely" were terms often used highlighting the significance of the architecture and environment within the Day Hospital. Other studies support these findings by suggesting that colour can assist with orientation within healthcare settings (Rousek and Hallbeck, 2011), including people with reduced cognition (Gibson et al. 2004). Colour can be used to manipulate areas to feel more spacious (Bosch et al. 2012), and reduce light reflection which has been shown to induce anxiety and impair performance in other populations (Winterbottom and Wilkins 2009).The architecture of the Day Hospital gave the impression of flow, there was not only a sense of space, but the large amounts of glass connecting various sections of the Day Hospital, including the gardens, generated aesthetic sensory connections.

The findings suggest that the colours, textures, pictures and spaces of the Day Hospital environment gave a tangible backdrop to a positive and welcoming sense of place for older people with frailty. Todres et al. (2009) suggest that feelings of dislocation can occur if a person is away from their sense of place, familiar environment, comfort and security. For many of the participants in this study, their first attendance at the Day Hospital had been difficult, the volunteers retold their experiences and observations of the anxiety and uncertainty people experienced. Furthermore, we discovered that their lives often already felt disordered, so to enter an environment which they may have expected to be cold, clinical and medicalised, and find it warm, bright and homely brought some sense of ease for people. If, our ways of knowing are felt through our bodies and senses (Galvin and Todres 2011, Gendlin 1982, Todres 2008), then we cannot separate our perceptions of the world, our interactions and sense of self-identity from our environment. The study findings uncovered that physical environments are an important element in constructing a positive sense of self-identity in older people with frailty, by providing a temporary space of familiarity and security to people who may be experiencing multiple changes and losses through their condition.

10.4.2 That all important cup of tea

Feelings of homeliness and hospitality observed within the data collection were substantiated by the felt experience of others. Provision of food and drink to patients and their relatives made people feel welcome and replicated unexpected yet socially familiar processes. Beyond the potential for nourishment provided by this type of hospitality, these acts of ‘welcoming’ cultivated a nurturing setting, and a space for the potential of positive engagement (Todres et al. 2009). Whenever I observed this within the Day Hospital it reminded me of a page from one of my sons’ books.

> *“In Britain, a cup of tea is the answer to every problem.*
> *Fallen off your bicycle? Nice cup of tea.*
> *Your house has been destroyed by a meteorite? Nice cup of tea and a biscuit.*
> *Your entire family has been eaten by a Tyrannosaurus Rex that has travelled through a space/time portal? Nice cup of tea and a piece of cake. Possibly a savoury option would be welcome here too, for example a Scotch egg or a sausage roll.”*
>
> *(Walliams 2010)*

Food and drink are basic human needs that impact upon our physical, psychological and social states in life (Hamburg et al. 2014), in the UK drinking tea holds a particularly strong cultural significance (Wang 2011). When tea was initially introduced in the 17th century it was a drink for the wealthy, sold as a ‘cure all’ remedy for several ailments and illnesses (Awasom 2011). Tea customs both then and now centre around comfort, care, gift giving and hospitality. Tea breaks are a time to relax and socialise with colleagues, afternoon tea is a time to indulge in niceties and share this with others (Wang 2011). Through shows of hospitality the Day Hospital presented itself as an accepting environment, for those who entered with trepidation regarding how they would be perceived, the offering of food signalled not only that this was a place where the meeting of basic human needs were important, but where the older person was expected and wanted. Food can be considered one of the most basic forms of offering (Heal 2008), a gift offered to another as a symbol of welcome. From the beginnings of human civilisation, the gifting of food has been culturally embedded in our daily lives (Hamburg et al. 2014), Berking (1999) highlights how sacrificial food was shared in ancient times to demonstrate the value of the individuals receiving. This ‘basic’ offering is a way of connecting with others, to make people feel welcomed; to then later remember how that person likes their tea, adds further dimension of value, they have been listened to and their choices acknowledged and venerated. It can represent an intention to form a relationship (Berking 1999). This offering was not only for the patient but extended to their relatives, a nod to their importance in this intended relationship. Hamburg et al. (2014) further suggest that the offering of food by those who are empathetic to the needs of the receiver structures a reciprocal process of emotional regulation and positivity.

Eating together and sharing food can also symbolise community (Andersen and Brünner 2020), where interactions with others can establish and reinforce social connections (Symons 1994), examples of which were observed within these findings. Social activities synonymous with eating and drinking form the basis of many kinship characteristics (Lashley and Morrison 2011). As we know that many older people with frailty entered the Day Hospital with underlying feelings of ontological insecurity, disconnection and being ‘the others’; acts of hospitality appeared to cultivate a culture of belonging. Older people were welcomed into the Day Hospital as a place which had potential for people to feel that they belong, and as they returned week by week, the same hospitality, offerings and welcomes became rituals. A known entity, secure in the knowledge that you would get a cup of tea.

The relationship between hospitals and hospitality is not new, Brotherton (1999) discusses hospitality in terms of welcoming strangers or guests, showing kindness and providing security. The foundations of modern hospitals have developed from ancient Christian hospices that provided not only care for the sick, but also shelter for pilgrims and strangers and food for the poor (Retief and Cilliers 2010). If we consider this in context of the ontological security experienced by people entering the Day Hospital, these elements of hospitality seem essential foundations of any hospital encounter. Pizam (2007) stated

> *“the difference between hospitals and hospitality is “ity” but that “ity” can make a significant difference in the recovery of hospital patients.”* *(Pizam 2007)*

The losses that people have experienced, the fraying of their life strands, can feel overwhelming at times, the pace of life can seem chaotic, yet these acts of hospitality appear to slow that pace down, allowing the older person to take stock of what is happening and relax into the environment. Pizam (2007) emphasises the ‘ity’ as a philosophical ideation, to serve and be dedicated to meeting a person’s needs and wants. He suggests that to experience true hospitality it needs to be a culturally embedded ideology throughout the entire organisation. I suggest that this is what the findings of this study show us, a philosophy of hospitality permeates the staff and volunteers at all levels, from the receptionist’s warm welcome to the manager making a round of drinks. This philosophy is not only evident between staff and patients but also amongst each other, making tea, sharing food, hugging, covering work for each other, all these actions are hospitably centric in nature and welcoming.

Throughout the findings there are several descriptions of being made to feel welcome within the Day Hospital, when we reflect upon what feeling welcome means, we can probably recognise it as a fundamental human experience and one that relates to many situations in our lives. Feeling welcomed generates positive emotional responses, when we feel welcomed we can relax, be ourselves and be open to positive interactions and engagements, feeling unwelcomed as (Lacey 2015) suggests can make us introverted, excluded and question our worth. The concept of Hospitality as Brotherton (1999) discusses it, i.e. welcoming strangers, showing kindness and providing security, feels somewhat one directional. The findings show that hospitality is provided by the staff and volunteers to the patients, yet there was also evidence of this being a reciprocal exchange. The chat over a cup of tea, starts to construct the foundations of safety and trust for the older person, but also enables the staff and volunteers to begin to build relationships. It sets the milieu as a safe space where both parties can contribute equally. Additionally, if the hospitality was not well received then these processes may be somewhat thwarted, in this way the benefit of hospitality within the Day Hospital is reliant not only on those providing it, but also those receiving it in order to co-construct a hospitable environment.

Pizam (2007) speaks from a hospitality management background when he talks of teaching staff to treat people as they would like to be treated, yet we can see this very element embodied in the narrative and observed findings of the Day Hospital staff and volunteers. Their words and actions show us that they empathetically imagine (Galvin and Todres 2011) what it is like within the patient’s world, this generates not only compassion but also a sense of realistic expectations of what could be achieved. By the staff and volunteers imagining themselves in the shoes of the patients and their relatives, they may be unwrapping and drawing on their own shared humanity, their own vulnerabilities and awareness of their own being or indeed potential non-being (Todres 2008; Whitaker 2019). In the volunteer focus group, Sarah was quite clear in her visualisation of herself in the place of the patients; not yet but… eventually. The Day Hospital demonstrated a very levelling culture, and evidence of this insightful and compassionate care is what enabled a sense of togetherness.

10.4.3 Building relationships, embodied knowledge and togetherness

Relationship building was another process embedded within the wider hospitable culture of the Day Hospital. I have discussed the association between identity and symbolic interactionism at various stages in this thesis, from a symbolic interactionist view, sense of self-identity is a social construct developing within the relationships and social interactions made, and the shared meanings of these relationships and events (Kaplan et al. 2006; Blumer 2018). With this is mind, the interactions and relationships constructed and established within the Day Hospital would directly contribute to the construction of sense of self-identity for the older person with frailty. In the previous chapter I summarised the experiences of older people with frailty as living with ontological insecurity, as part of this, the findings show that older people attempted to make sense of their changing world through the sharing of stories and narrations of their past, present and future lives. As identified in the literature review, some of the earliest literature in the area of self-identity in frailty focused on the construction of identity through narrative accounts, a process that we all undertake all of the time (Taylor 1992; Kaufman 1994; Grenier 2006).

Narrations of the self are not static and linear, they are created and recreated over time (Degnen 2005; Bamberg 2011), some elements of these self-narrations may be more constant, yet others may ebb and flow dependent on the moment. Narrations of the self therefore require a person to order their life characters, and events within space and time (Bamberg 2011). Temporality is the term used to describe time as we humanly experience it (Hemingway 2011). The concept of temporality is therefore important in the construction of identities and an elemental factor in the building of relationships. The findings show us that concepts of time, as experienced in the lives of older people with frailty, can fluctuate. People describe moving more slowly, activities of daily living taking longer to achieve, all the while, life and the world around us can appear to be moving quickly, children grow up, technologies change, our bodies change. Within the Day Hospital older people with frailty often talked about things that had happened in the past. Many spoke of their children, their work and their partners, and frequently I heard the phrase “when I was your age”. Degnen (2005) suggests that older people who narrate their present lives through past experiences may be seen as ‘stuck in the past’ and healthcare professionals may try and ‘move’ them to the present in order to provide rehabilitation. The findings of this study show however, that in the Day Hospital this was generally not the case. Overall, there was a recognition of the importance of temporality regarding self-identity. Not in the sense that staff or volunteers would be conscious of the term temporality, but rather they seemed to recognise that sense of self-identity was not a fixed concept, that it was formed in part by past experiences, by elements of a person's world which they found important. Staff and Volunteers listened to people speak, topics were varied, many initially appeared somewhat unrelated, however it soon became clear that recognition of what the patient presented as relevant whether from the past or in the present was often more important that the subject itself.

As people began to feel listened to, more detail would develop about their condition, their abilities, their fears and anxieties. The resistance that they may have presented at the start of their treatment appeared to change to eagerness to participate. Recognition of the importance of this by staff was seen, detailed particularly in the focus group as Nina talks about her experiences as an Occupational Therapist. Nina identifies the importance in recognition of people's stories, their fears and hopes. She spoke about the emotions these type of connections generated not only for the patients, but also related this to how she processes her own fears and story. By listening, acknowledging and understanding a person's narrative, staff at the Day Hospital were able to recognise debilitating factors and this became a starting point to build upon for their relationship and therapeutic practices.

Trusting relationships and connections began to develop and once established, engagement in therapy appeared to become more substantiated. This was further evidenced by the sadness that many of the patients and their relatives expressed when their time at the Day Hospital came to an end. Staff and volunteers gave a part of their selves, they shared personal moments, such as birthdays and Christmas celebrations, activities which are more associated with kinship and family rather than a healthcare setting. Kinship has been described as the primary organiser in human relationships (Bailey 1988), research suggests that feelings of kinship construct social coherence amongst a community (O'Brien 2017) and serve as bridges across social groups (Regan 2011). The findings of this study illustrate symbolic acts and feelings of kinship that were established between those in the Day Hospital. The development of these feelings of kinship between health care professionals and patients formed ties which are different from other healthcare interactions and relationships.

Feelings of kinship enabled a sense of belonging, as if in a family. Sense of belonging is considered essential for people to feel that they are part of something and can actively contribute to their wider social systems (Shifron 2010, Todres et al. 2009). The older people in this study had previously lost many of their kinship connections, their tightrope threads, therefore acts of kinship and connection within the Day Hospital served to reinforce feelings of relatedness and stability within the world. Sense of belonging enabled people to feel valued, relaxed and secure (Halse 2018). The relationships developed within the Day Hospital provided positive and reciprocal attachments, trust and security which further strengthened the ontological security the patients needed to progress in their rehabilitation (Giddens 1991, Mansvelt et al. 2014).

Knowledge from the deep multi-layered understandings that these relationships and connections constructed was used by staff and volunteers to shape interactions and interventions that were meaningful and relational for the patients. We see practical examples such as when the volunteers, realising a patient no longer plays cards due to moving into residential care, brought a pack of cards to play with her each week. Or when the patient who used to wind surf was teamed up with a nurse who also surfed and sailed. This type of meaningful knowledge, separate from that of the science of their clinical conditions, was then empathetically utilised as a base for ongoing therapeutic interactions. Galvin and Todres (2011) describe this way of knowing as embodied relational understanding. Embodied relational understanding describes ways of knowing which attend to the richness, movement and context of a person’s world. Through the building of relationships, recognising temporality, sharing of experiences and interdisciplinary cross working, staff and volunteers demonstrated being embodied practitioners. Through empathetically recognising and understanding another’s world Day Hospital staff and volunteers can utilise and combine with the more objective science of illness and relate to patients and their relatives in an embodied way.

The findings showed that the older person with frailty was often consumed by thoughts of their bodies, their ailments, their pain and their bodily inabilities. Part of the loss of sense of self-identity arose from the older person experiencing times in their lives when they felt that their entirety was reduced to their physical symptoms, sense of self-identity for some, centred around their ‘failing’ bodies. As I described in Chapter 1 the clinical condition of frailty is predominantly defined by the objective measurement of physical losses (Fried et al. 2001; Rockwood et al. 2005), it is not surprising therefore that older people entering healthcare environments may expect to experience a reductionist view of themselves and their bodies. The findings of this study suggest that the culture within the Day Hospital constructs and supports embodied practice, ways of knowing allowed the staff and volunteers to re-engage the patient in their own ‘personhood’ (Todres et al. 2009), and insiderness (Todres et al. 2009), focusing not on their loses but their strengths, capabilities and intrinsic capacities. This contrasts with the practices highlighted in similar environments where subjective experiences, self-narrations and personhood is reduced to a list of problems to be solved (Kaufman 1994).

10.5 Implications for future practice

Fear is undeniably and understandably a factor in the experience of living with frailty, as ontological security is challenged, daily life can become laden with anxiety and unpredictability. This study has shown how frailty is often experienced and acknowledged at a crisis point, although the condition of frailty could better be interpreted as pre-existing vulnerability.

The identification of those at risk of frailty through the GP contract (NHS England 2017) and the utilisation of the Comprehensive Geriatric Assessment goes some way to implementing more integrated and holistic approaches to the management of frailty. However, the line between being at risk of frailty and experiencing frailty is thin and precarious and simply identifying those at risk is not enough. As it stands GPs are only called to action if a person’s frailty risk is identified as severe, missing from the current frailty toolkit is the importance of the social dimensions of frailty which this study has shown are clearly significant in the construct of the individual. Focus must shift from using the accumulation of deficits as an objective measurement of the impact of frailty, to looking to understand, recognise and utilise the current capabilities a person has and building upon these to open new potential and possibilities for the older person.

Policy makers, practice influencers and those working with older people with frailty need to no longer view frailty in terms of its separate biological and social components, but rather frailty as an embodied experience of the lived self. Living with frailty, as a long term illness, requires learning to change and adapt to new ways of living within a world which can feel unstable and unpredictable. This is not just within our physical bodies but also within our relationships, interactions and existentially in terms of sense of self-identity. Focus on the lived self and all that contributes to it, rather than the individual components, should enable older people to feel seen, valued and capable.

Older people are often represented as costly to the NHS and social care services, NHS spending is continually reviewed in order to minimise costs and frequently provisions which considered to be unnecessary ‘soft services’ or ‘add ons’ are the first to be cut. This study highlights however that it is these types of less visible provisions, such as hospitality, which lay the foundations for engagement in rehabilitative processes. Ultimately, the successfulness’ of these processes would reduce NHS spending. Service providers should consider the importance of ‘invisible’ humanising practices when reviewing cost services and their importance in creating feelings of safety and security to fully engage in therapies.

10.6 Strengths and limitation of the study

As with all research there are strengths and limitations to this study which should be considered alongside these findings. As discussed the methodology and practicalities of ethnography provided a strong framework to understand the multiple facets of culture both at collective and individual levels (Schensul and LeCompte 2013; Atkinson 2015; Fetterman 2019). When looking to understand cultures, variations in the individual members responses and actions may occur based on a person’s interpretations and story (Nastasi and Hitchcock 2016). However, within this study, the data collection methods used, ethnographic focus on interactions and cultural practices, and the inclusion of groups other than the older people under observation, meant that the co-constructed and culturally shared meanings of a collective within the Day Hospital could be reflected in the findings. The depth of observational data and immersion into the

Day Hospital, enabled me to reproduce accounts of the complexity of group behaviours and interactions which may not have been highlighted through other research methods. In saying this, I must also acknowledge that my observations, analysis and interpretations cannot be separated from my own life narratives, personal beliefs, values and perceptions of the world. From this perspective the interpretations and conclusions described in this chapter derive from the co-construction of data between myself, and those who participated in the study.

Despite the comparatively large timeframe, scale and depth of the data collected in this study to some similar studies, I also recognise the data underrepresents older people with frailty from culturally diverse backgrounds, and those living outside the conurbation of the Day Hospital catchment. And I must consider that the behaviours, rituals and thoughts of older people from differing cultural backgrounds may not be represented within these findings.

Furthermore, although there were no exclusions to participation[2] during the observational stage of the study, patients who were recruited to the focus groups were initially identified via their therapy teams. Those that enrolled, actively participated with the discussions and appeared keen to both share their stories and listen to others, however there were people identified by the therapy teams who did not want to participate in the focus group discussion. Reasons for decline included “not being their thing”, and not wanting to sit in a group to talk, and therefore the focus group narrative may miss the views of people who chose not to share their thoughts and stories in this way. Furthermore, a decision was made not to include those with significant communication disorders or difficulties within the focus group discussions. Therefore, these findings do not capture the voices and narratives of those who fall in to either of these groups, which may have differed.

The limited number of previous ethnographic studies in this area have focused on the understandings, experiences and interactions of older people with frailty within their own homes (Nicholson et al. 2012; Skilbeck et al. 2018). As far as I am aware this ethnographic study is the first to explore the construction of the

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[2] Other than participant choice

identities of older people with frailty within an NHS Day Hospital, it is also the first study I can find in this environment to present contributions from multiple actors within the worlds of the older people and their Day Hospital interactions including Staff, Volunteers and Relatives. These contributions add a range of perspectives which enhances depth and credibility of the findings.

10.7 Implications for future research

The stigmatisation of groups of older people both with and without frailty continues to devalue and reduce the identities of those affected to their inabilities rather than celebrating their capabilities. Although work to understand frailty has progressed in recent years, with the recognition of psycho-social elements of frailty now more readily accepted, I suggest we still l have some way to go in understanding the significant impact that frailty can have on sense of self-identity, and how the way we think and talk about frailty may perpetuate feelings of reduction and objectification. Over the past year we have faced a coronavirus pandemic, the language and discourse surrounding which substantiates my argument that our social perceptions and attitudes towards older people still have a long way to go. Mass shielding strategies based on age in addition to clinical condition, homogenised millions of older people and labelled them as vulnerable, negating any individuality, diversity or capability within this group of people. Although care was shown for these ‘vulnerable’ older people with volunteers coming forward to supply food and services to those shielding, there remains a paternalistic air to the sentiment. One which I suggest reflects the way many of us think and talk about older people in society.

These thoughts were reflected in a recent report which highlighted the continuing negative attitudes towards older people. The report looked at the language used by the government and the media in relation to age and ageing demographic change and found that older people were often framed as a costly ‘crisis’ by politicians and overlooked contributions of older people within society. Older people are also often depicted as being in competition with younger people in ‘boomer vs millennial’ narratives (Centre for Ageing Better 2020).

My study has highlighted the impact of such thought processes on the ontological insecurities and sense of self-identity in older people with frailty. Further research into the impact of frailty on sense of self-identity is essential if we are to fully understand experiences and improve services for older people with frailty. The study also highlights the impact of frailty on the sense of self-identity for the spouses and carers of people with frailty, a greater understanding of which would provide more insight to providing effective services that can be continued and maintained within the home environment.

Chapter 11 Conclusion

In this study I set out to understand how sense of self-identity in older people with frailty is understood, constructed, and enacted within an NHS Day Hospital setting. The literature highlights that engaging older people in rehabilitative services can be difficult, especially for those living with frailty. The Day Hospital however had a good reputation and was highly valued by older people who were happy to attend and engage in rehabilitation, I wanted to understand why this was the case.

The findings address the gap in the literature regarding our understandings of the processes and cultural structures that support a positive sense of self for older people with frailty, and how these can be harnessed to maximise therapeutic interactions and potential. I discovered that those living with frailty wanted to attend the Day Hospital because of how they ***felt*** when they were there.

Older people are often portrayed as weak, vulnerable, and dependent, concepts which can contribute to feelings of low self-worth, insecurity, and fear of the future. In the Day Hospital however, older people living with frailty felt welcomed, listened to, and valued. In healthcare we often focus on the visible actions and what we do, this research highlights that it is just as important to consider invisible aspects and how people feel as this affects their level of engagement. Positive feelings were experienced because processes within the Day Hospital recognised the multiple layers of self that a person can experience, alongside the unsteadiness and insecurity that the condition of frailty brings.

This was achieved because staff and volunteers at the Day Hospital fostered a culture where positive sense of self for both patients and staff was supported and recognised as foundational elements to continued therapeutic engagement. Additionally, the physical environment of the Day Hospital created a therapeutic space, where patients, relatives, staff, and volunteers could enjoy minimal physical barriers, bright colours, and outside spaces. Staff worked ***with*** patients and their relatives in humanising ways where focus was not only person centred but also incorporated embodied ways of knowing, subjective experiences, and the relationships between each other.

This positive culture developed from the staff and volunteers who themselves felt accepted, valued, and cared for in the work environment. Staff and volunteers felt that they had voice and influence in the Day Hospital and these feelings of value, control and empowerment seemed to transcend to the patients and relatives. These ways of being may only be effective however, within a cultural milieu that is based on care and compassion for all involved. A culture where healthcare workers are not disembodied from those that they care for, a place where older people are not objectified, but are truly seen as individuals with potential and capability. The construction of a nurturing, accepting, and compassionate work culture is an essential foundation to support humanising and embodied practice for older people with frailty.

I found that the nurturing and accepting culture created within the Day Hospital impacted upon not only the service users but also service providers, supporting positivity, wellbeing and staff happiness. Processes and behaviours within the community of the Day Hospital such as breaking down barriers across interprofessional working, and colleague compassion and kindness created a sense of community spirit which lifted and motivated staff, volunteers, patients and relatives alike. Patients were at the centre of their own care as staff in the unit worked together, across disciplines and without negative hierarchical officialdom in order to meet the patients’ needs and wants. They were hospitably centric in their care delivery and seemed to understand each other’s personalities, strengths and weaknesses, and insightfully utilised these as a combined force to provide individualised care for the patient. This type of integrated care felt as though it could only work in a setting where the culture was supportive and where individuals within it felt secure. There was a deep understanding of each other, and this was further evidenced by the way in which the staff and volunteers shared their personal lives and intimacies within this work environment.

What I found unique in my observations, collection and analysis of the data, was coming to the realisation that the embodied way of knowing that staff and volunteers demonstrated within their patient relationships, was evidenced with in their relationships with each other. Kindness and compassion were not observed as one directional concept from staff or volunteers towards patients, rather they appeared to be engrained in the day to day culture of the unit. Daily, staff used physical touch to demonstrate their care for each other through hugging, the warm greetings experienced by the patients at the reception were replicated within the staff office and volunteer kitchen. The domestic lives of the staff were not fully separate to their lives within the Day Hospital, as physio Bethany reflected how there was nothing in her life she wouldn't share with her colleagues, and significantly, nothing she felt they wouldn't wanted to hear. There was general agreement with Bethany that its being able to share the "personal stuff" that makes the team feel close. This reflects the work of Gordon (2020) who highlighted the importance of healthcare staff feeling able to bring their outside lives into work contributing to meaningful relationships and effective teamworking.

Bethany suggested that the closeness of the team is constructed through this ability to share parts of their lives with each other. 'Ways of knowing' each other were evidenced through the personalisation of interactions observed, if someone presented themselves as 'different to usual' they would be checked on. The 'checking' could be in form of a gesture for example, making a cup of tea for someone without asking them (yet knowing their favourite cup). Similar to what I observed with the patients, the giving, receiving and sharing of food appeared significant to these co-worker relationships, the ritualistic practice of the 'bring and share' was well established and actioned for multiple culturally significant occasions such as birthdays, weddings, baby showers, retiring and sometimes appeared to be 'just because'. The activity of preparing a dish and then sharing with others was more than a social nicety, eating together created a shared space, a time to step away from the desk and paperwork and reinforced the feelings of kinship within the group. Thought was shown in the preparation of dishes with attention to dietary requirements, a symbolic gesture of encompassing all, everyone belonged. These findings demonstrate how staff expand their relational focus from the patients to each other. They recognise uniqueness in each other but also value the interdependence that is required to effectively care for patients and each other (Nolan et al. 2004). There was a human connectedness and attentiveness in their ‘being with’ each other which resonates with concepts of relational understanding (Galvin and Todres 2013).

We are living in times of significant financial and systematic pressures on the NHS, from an external objective view many of the processes revealed in this study such as providing refreshments and spending time building relationships are seen as ‘niceties’, ‘add ons’ which can be removed if cuts to services are to be made. When discussing these findings with a nurse colleague she laughed and said, *“so you have spent four years working out that people like sandwiches”,* although somewhat said in jest, I would suggest that this view is representative of what we see in modern healthcare. It is ‘nice’ to offer someone a cup of tea, but not essential. It is good to be kind to each other, but only if we have time. This research however suggests that **these processes are not simply add ons to care, but a fundamental part of care.** When we consider the insiders view of people living with frailty, how they feel about themselves, their bodies and their lives, we can see that humanised, embodied practices and interactions which encompass the processes outlined in the findings of this study can and should be seen as essential and fundamental elements to an effective intervention for older people with frailty, gradually enabling people to gain confidence in themselves and their world and maximise their capabilities.

As previously highlighted there has been many incidents where the organisational culture of the NHS has been called in to question (Francis 2013; Powell and Walsh 2019). Healthcare workers are under high levels of stress on a daily basis, caring for people in the most intimate of ways, which can result in staff burning out, overcome by the volume of people, conditions and processes that they encounter, and can lead to feelings of benign care and defensive coping mechanisms (Campling 2015). In 2014 the Day Hospital engaged with a local University to systematically examine their services and identify ways it could be improved to provide a better quality of care. They did this through the process of practice unit accreditation, a process based on teamwork, collaboration, and emancipatory change that reflect the perspectives of patients, relatives, staff, and volunteers (Board et al 2019; McCormack 2004). This process empowered staff to seek and enact changes to their practice that would enhance their work and patients experience. This process enabled the team to further recognise and appreciate the skills set of the whole team, adding to their culture of respect for each other, which subsequently cascaded to the patients attending the Hospital (Board et al. 2019). The process was funded by the Trust and widely recognised at the Trust as an example of excellent team working and a model they wanted to roll out to different areas. It is also worth noting that the prior engagement in this process was not overtly evident to me through my observations, suggesting that the changes felt have been culturally accepted and embedded within daily practice.

The Day Hospital faces the same pressures as many other services within the NHS, yet this research highlights that they have created a cultural environment where ways to process their emotions and experiences is supported and encouraged. Working within supportive teams can buffer the difficulties faced of wider dysfunctional organisations (West et al. 2017). Managers within the Day Hospital enable others to connect to each other in humanising ways, recognition of the importance of sense of self for patients, relatives and staff alike empowers them to work in compassionate humanised ways. People feel heard and cared for on multiple levels. Compassionate leadership, and the compassionate care that this produces enhances the intrinsic motivation of all involved in the relationships within the Day Hospital. Staff feel safe to question, challenge and innovate new ideas, within a culturally non-hierarchical workplace free from blame and fear. These feelings of safety appear to permeate the interactions with patients and relatives.

Within this thesis I have used the words compassion and kindness, often interchangeably as that is how these feelings appeared to be experienced. Kindness was an embodied practice; it wasn’t something that was added on to care but embedded within it. Campling (2015) discusses the concept of intelligent kindness, calling us to consider the conditions that are required for kindness to be enacted within health settings, highlighting its importance in the nature of being and as such is a requirement for most organisations to progress. Campling (2015) uses the concept of a virtuous circle of kindness to demonstrate how cultural behaviours can nurture the wider organisational system.

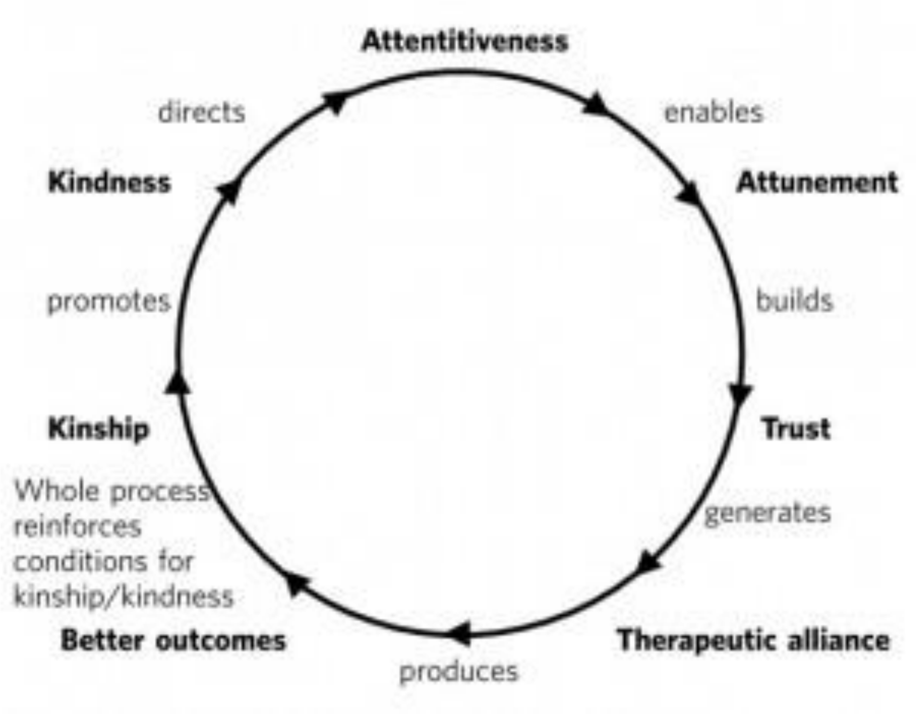

Figure 25: Intelligent Kindness: a virtuous circle.

(Campling 2015 pg. 4)

Kindness generates attunement to patients which builds trust and therapeutic relationships, better outcomes, and feelings of kinship, belonging and positive sense of self-identity for patients and staff alike. These ways of being require not only commitment from individual staff but also organisations that enable and allow for progress.

Through the processes enacted within the Day Hospital and the organisational structures that enable them, positive sense of self identity is strived for and often achieved for staff, volunteers, relatives, and patients.

Modern healthcare continues to objectively view interventions for people living with frailty. This study has revealed insights from the insider's perspective, concepts such as hospitality do not appear to be given significant value within our stretched healthcare service yet eating and drinking are essential parts of our cultural practices. By negating important cultural practices, the benefits they produce are devalued. Basic human needs are taken away, and care can become task orientated rather than humanising.

This study contributes new insights into the importance of enabling older people with frailty to feel welcomed in a healthcare setting, in order to break down preconceived notions regarding the condition of frailty and ageing, and interventions that may be beneficial to engage in. With ongoing reduction and redistribution of NHS resources it is often the ‘softer’ aspects of healthcare which are the first services to be cut, but this thesis has highlighted that these aspects are fundamental and should be prioritised if we want healthcare services which are going to be truly responsive to the needs of older people living with frailty.

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Appendix 1 – Study Protocol

How does the culture of a Day Hospital support the identity needs of frail older people?

SHORT STUDY TITLE / ACRONYM:

IDENtiFy: Supporting the identity needs of frail older people

This protocol has regard for the HRA guidance and order of content;

IRAS Project ID: 226808

Sponsors: Bournemouth University

STUDY TITLE. How does the culture of a Day Hospital support the identity needs of frail older people?

SHORT STUDY TITLE. IDENtiFy: Supporting the identity needs of frail older people

PROTOCOL VERSION: 2.0 7th August 2018

RESEARCH REFERENCE NUMBERS

IRAS Number:	**226808**

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date:

..../....../......

Name (please print):

....

Position:

....

Chief Investigator:

Signature: Date: 15/06/2017

....

Name: (please print):

Chantel Cox

KEY STUDY CONTACTS

Chief Investigator	Chantel Cox Email: [redacted]
Sponsor	[redacted]
Funder(s)	[redacted]

	[redacted]
Key Protocol Contributors	[redacted]

STUDY SUMMARY

People are living longer than ever before, in the last 40 years alone the number of people aged over 65 has increased by 46% representing 18% of the total population (ONS 2015). Frailty is a major health condition related to aging and its increase is reflected in these demographic trends. Half of all people in the UK aged over 85 are now estimated to be living with frailty and this is expected to rise. The language and discourse around the condition can act as a barrier to engaging with older people who do not wish to be defined as frail (Age UK and BGS, 2015). People experiencing frailty often report low levels of wellbeing particularly in relation to their sense of identity and increasing dependency (Andrew et al. 2012), which in turn can lead to poorer health outcomes and reduced engagement in therapeutic interventions (Twigg and Martin, 2015).

To date, frailty research has mainly focused on physical interventions and measurements of frailty. There is little exploration of the socio-cultural experience of frailty, particularly in relation to how frailty impacts upon identity and how the identity needs of a person with frailty can be met within service provision. Christchurch Day Hospital (CDH) has an innovative service for frail older people and, service users highlight that the positive way that they are made to feel about themselves has an impact on their healthcare outcomes. However, it is unclear what processes underpin these relationships between identity and outcomes.

Study Title	How does the culture of a Day Hospital support the identity needs of frail older people?
Internal ref. no. (or short title)	**IDENtiFy**: Supporting the identity needs of frail older people
Study Design	Ethnographic Study
Study Participants	• [redacted] Day Hospital staff including nurses, doctors, physiotherapists, occupational therapists and therapy assistants, administrative staff and volunteers. • Patients attending the Day Hospital living with frailty

	- Relatives/carers of the above patients.
Planned Size of Sample Phase 1	- Day Hospital Observation
(Phase 2 Participant observation and focus groups.)	- Up to 10 staff - Up to 10 volunteers - Up to 10 patients - Up to 10 relatives/carers - In total up to 40 participants
Planned Study Period	36 months
Research Question/Aim(s)	How does the culture of a Day Hospital support the identity needs of frail older people?

In this ethnographic study drawing on constructivist perspectives the aim is to understand how patients' needs are met in relation to their sense of self and identity within a Day Hospital environment. The culture of the day hospital will be explored via observations, collaborative interviews, focus groups and documentary analysis in order to determine key processes which a) need to be in place to create positive identities and b) could be transferred to support future best clinical practice in other health care settings.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
[redacted]	Match funded student stipend = £7000 per annum Plus £1000 per annum research Supervisory Support [redacted] Access to continuing professional development (CPD)
Bournemouth University	Match funded student stipend = £7000 per annum [redacted] Office Space

	Access to continuing professional development (CPD) Access to Graduate school and postgraduate research training and development.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

Study Supervision Group

This study is part of a Doctoral project undertaken at Bournemouth University by the Chief Investigator and as such is supported by the Chief Investigators supervisory team.

The supervisory team is made up of;

[redacted]

[redacted]

[redacted]

This team has extensive experience working and researching within the NHS environment. The role of the supervisory team is to guide the planning of the research project, such that it is achievable within the expected timeframe and to provide clear guidance on the key monitoring milestones and keep a systematic record of progress. The majority of the team meet every two weeks. The supervisory team has and will continue to advise on, and contribute to

The scientific and ethical quality of the research proposal

The safety and wellbeing of participants.

The ability of the applicant to conduct the proposed research.

The availability of time and resources to achieve the proposed research objectives.

Active and effective arrangements to monitor and assess the progress of the research.

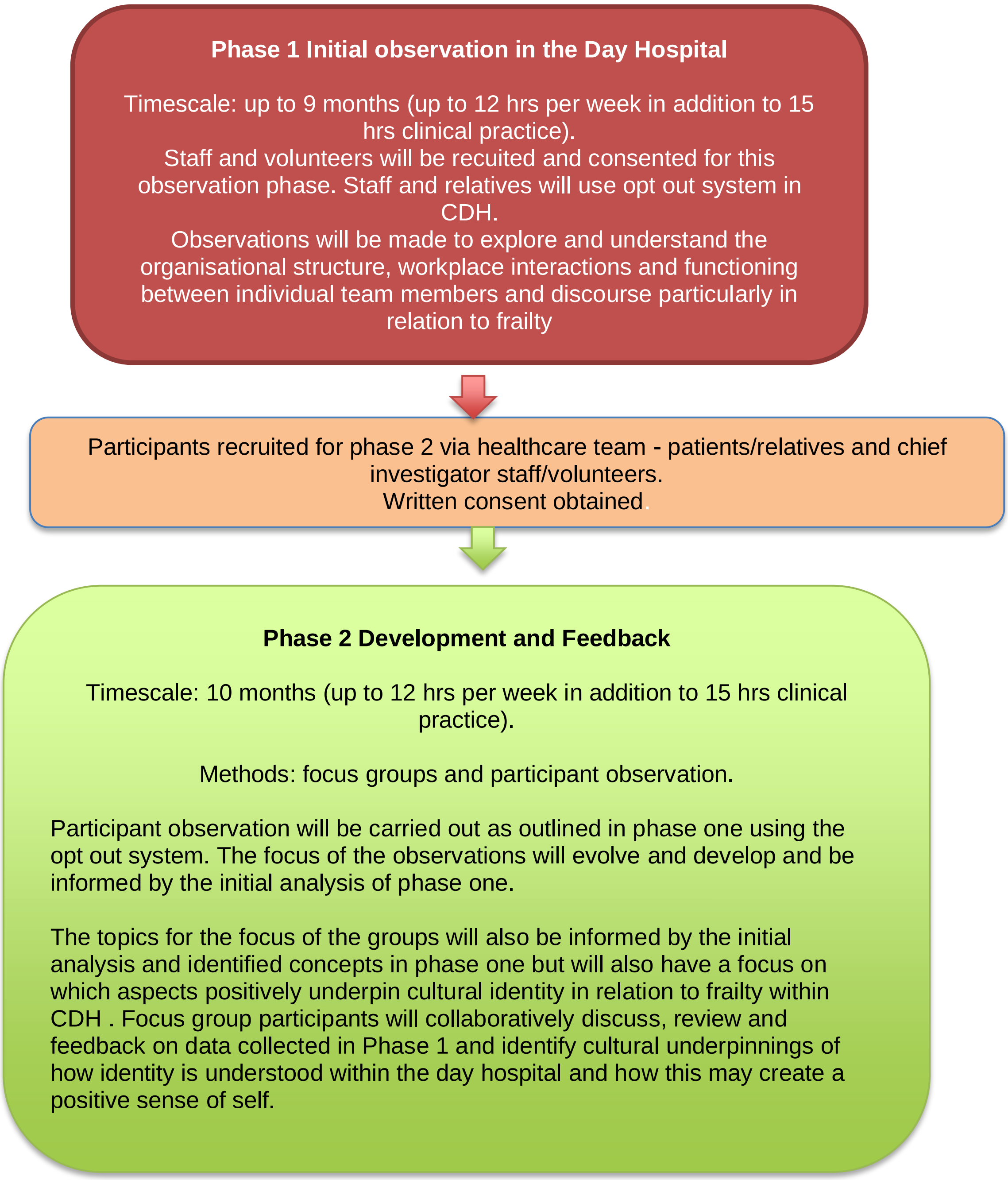
Appropriate arrangements to disseminate the findings of the research and ensure that the study adheres to Bournemouth University guidelines.

Patient & Public Involvement Group

The acceptability and design of this research project has been approved by a PPI group as outlined in section 8.4 of this protocol. This group will also form the basis of a patient and relative/carer study oversight group who will be invited to meet after phase 1 and 2 of the study to provide on-going oversight to the management of the study.

LIST of CONTENTS

STUDY FLOW CHART



Phase 1 Initial observation in the Day Hospital

Timescale: up to 9 months (up to 12 hrs per week in addition to 15 hrs clinical practice).
Staff and volunteers will be recuited and consented for this observation phase. Staff and relatives will use opt out system in CDH.
Observations will be made to explore and understand the organisational structure, workplace interactions and functioning between individual team members and discourse particularly in relation to frailty

Participants recruited for phase 2 via healthcare team - patients/relatives and chief investigator staff/volunteers.
Written consent obtained.

Phase 2 Development and Feedback

Timescale: 10 months (up to 12 hrs per week in addition to 15 hrs clinical practice).

Methods: focus groups and participant observation.

Participant observation will be carried out as outlined in phase one using the opt out system. The focus of the observations will evolve and develop and be informed by the initial analysis of phase one.

The topics for the focus of the groups will also be informed by the initial analysis and identified concepts in phase one but will also have a focus on which aspects positively underpin cultural identity in relation to frailty within CDH . Focus group participants will collaboratively discuss, review and feedback on data collected in Phase 1 and identify cultural underpinnings of how identity is understood within the day hospital and how this may create a positive sense of self.

STUDY PROTOCOL

How does the culture of a Day Hospital support the identity needs of frail older people?

1 BACKGROUND

Although the term frailty has been in use for a number of centuries, it has only been during the last two decades that frailty has been recognised as a distinct clinical syndrome. Frailty is usually described as a multidimensional health condition specifically associated with aging however differing ideas of the definitions of these ‘dimensions’ and elements of the condition has led to an absence of a universally accepted clinically operational definition.

People that have frailty do not always experience the same symptoms and it is not associated with a specific illness (Buckinx *et al* 2015), because of this variation frailty is often masked by other long term conditions and disabilities. This is problematic as many people with frailty also have disabilities however there are many people with disabilities who do not have frailty; frailty is the cause of disability in some people and the consequence for others (British Geriatrics Society 2014). These disparities can lead to patients being misdiagnosed and not receiving treatment that could potentially support their condition.

A number of models to assess and diagnose frailty have been proposed, however two main approaches are commonly used. The frailty index developed by Rockwood (2007) counts “deficits” and defines frailty as an accumulated score of these deficits. The more things you have wrong with you, the more likely you are to be frail. Rockwood defines a deficit as something that is wrong with you, a symptom, sign, disease or disability. His framework presents frailty as a state of multidimensional risk that can be measured more by the quantity than by the nature of health problems. Conversely the frailty phenotype model proposed by Fried et al (2001) identifies a number of key physical characteristics such as weight loss, exhaustion, fatigue, slow gait and weak muscles which in combination lead to the person experiencing a decreased physiologic reserve. Both of these models are underpinned by the theory that frailty occurs when a number of age related deficits reduces a person’s resilience to illness (Clegg et al., 2013). This is of significance because this leads to a higher risk of a sudden deterioration, following a relatively minor event such as an infection or change in medication (British Geriatrics Society 2014).

Frailty is a major health condition with its epidemiology reflecting an ageing society. Rates of frailty increase with age and half of all people in the UK aged over 85 are now estimated to be living with frailty and this is expected to rise (Clegg et al. 2013; Turner and Clegg 2014). In 2013 The Francis report (The mid Staffordshire Foundation Inquiry 2013) highlighted the significant shortfalls in the care of frail older patients. Since then Healthcare professionals and regulatory bodies have made moves towards providing more complete care for older people with frailty (Frail older people – Safe, compassionate care (NHS England 2014), however a recent report states that only half of those with frailty syndromes are receiving effective healthcare interventions (British Geriatric Society and The Royal College of General Practitioners 2015).

Acknowledgement of the potential impact of the condition of frailty has gone some way towards clinicians recognising it as a treatable condition; however perceptions around the condition itself still appear to be grounded within the biomedical models of illness. Many people, including those experiencing the condition, still consider that frailty is irreversible and synonymous with loss of independence and that it signifies they are entering into the end stage of their life (Lyndon 2016). This may be because contemporary literature in the area of frailty has focused heavily on defining the condition and developing therapeutic interventions based on the physical aspects of frailty such as muscle strengthening exercises, balance work and changes in diet (Fairhall et al 2016, Fried 2001, Xue 2011).

Although interventions are available to treat the physical aspects of frailty, the language and discourse around the condition can act as a barrier to engaging with older people who do not wish to be defined as ‘frail’ or ‘living with frailty’(Age UK and The British Geriatric Society 2015). Concepts such as identity, dependency and frailty are subjective and culturally constructed through people’s understanding of the world, the words themselves, and their lived experience of these concepts (Stephenson et al. 1999). People experiencing frailty often report low levels of wellbeing particularly in relation to their sense of identity and increasing dependency (Andrew et al. 2012). This is important as we also know that a diminishing sense of self or loss of identity can lead to poorer health outcomes and/or reduced engagement in therapeutic interventions (Twigg and Martin 2015).

Nationally a number of services exist to support the care of older people in the community including people living with frailty. One such service is Medical Day Hospitals (MDH). MDH provided centralised outpatient multidisciplinary assessment and short and long term therapeutic intervention (Young and Forster, 2008). Lately however in the UK there has been a national decline in MDH's (Parker et al., 2009) and a recent Cochrane review assessing the outcomes of day hospital care verses alternative forms of care (Brown et al., 2015) has highlighted a need for further research into the effectiveness of day hospitals including input from the service users.

Locally Christchurch Day Hospital (CDH) has developed an innovative service for the frail older person. The service is highly valued by the hospital trust and service users alike and there are many positive, clear, measurable outcomes in terms of physical therapy and medical recovery. People with frailty who use this service have highlighted that the way that they are made to feel whilst attending the day hospital had an impact on their outcomes; however, it is unclear what processes underpin these positive outcomes.

To date, frailty research has centred on reducing the risk of adverse health outcomes by focusing on physical interventions and measurements of frailty. However there is little exploration of the socio-cultural experience of the person with frailty, particularly in relation to how the identity needs of a person with frailty are met and how frailty impacts upon a person's understanding of self and identity. As a condition frailty has the potential for deceleration however to achieve this, development of effective therapeutic relationships within services is essential. It is vital to understand how healthcare professionals can support the identity needs of frail older people when delivering services within a healthcare environment.

2 AIM

This study aims to understand how patients' needs are met in relation to frailty and their sense of self and identity through exploration of their socio-cultural experiences of care in order to determine key processes which could be transferred to support future best clinical practice in other health care settings.

3 Theoretical framework

The theoretical framework that guides this ethnographic study is based within the constructivist paradigm where the researcher believes that people construct their world view based on their experiences, social interactions and interpretations (Gergen 2001). These realities are unique to the individual, yet they may share similarities with others that experience similar or shared events or interactions. In relation to healthcare an example of these shared experiences may be being diagnosed with an illness or being given a specific planned treatment/intervention. Social construction theory places an emphasis on how people develop meaning within their world and also develop a sense of their place within it (sense of self-identity). The researcher assumes the position that the concept of identity is socially constructed, meaning they believe that a person's sense of their identity is created through social processes, interactions and behaviours.

Ethnography generates an understanding of culture within a particular group and setting (Reeves et al. 2008). It allows immersion into a community to gain a deep knowledge about the intricacies and inner workings of a group of people and offers the opportunity to observe behaviour or beliefs through actions which may differ from those shared verbally (Fetterman 2010).

Key features of ethnographic data are their richness and depth. The need for extensive field work and the time spent within the day hospital will allow for the observation of behaviours, discourse or rituals which may be sporadic or emerge as sequential patterns of behaviour that may not be observed or identified using other methods.

Using ethnography within a healthcare setting has been advocated by a number of authors as it can facilitate accessing health beliefs and practices, subsequently aiding understanding of behaviour associated with health and illness (Savage 2000, Van der Geest and Finkler 2004). Brewer (2000) also highlights the significant contribution that an ethnographic approach can make to policy research, as this study is part of a clinical academic PhD this method was also chosen to provide cumulative evidence that will provide new knowledge in order to inform decision-making and to develop clinical practice guidelines from the results.

4 RESEARCH QUESTION/OBJECTIVES

How does the culture of a Day Hospital support the identity needs of frail older people?

4.1 Research Objectives

i. Understand the discursive and behavioural processes which contribute to the identities of frail older people within the day hospital.
ii. Understand how the processes linked with construction of identity in relation to frailty impacts upon engagement in services.
iii. Determine what processes need to be in place to support
    i. A positive sense of identity for frail older people.

   ii. Positive and full engagement in services

iv. As this is a clinical academic PhD a further objective will be to recommend effective strategies for positively supporting the identity needs of frail older people in a healthcare setting through the development of clinical practice guidelines relating to identity support.

4.2 Outcome

- This research will contribute to a greater understanding of the relationship between identity and frailty and the positive mechanisms within a health services environment that support that relationship.
- Respond to the lack of socio-cultural experience literature in relation to frailty and identity
- As part of a clinical academic PhD this research also offers the potential for an active impact on current clinical services to people that are living with frailty within the local community and development of clinically relevant processes for future practice.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

5.1 Study design:

This study will use an ethnographic approach to address the aims of the project and to provide a contextualised understanding of the created culture of identity within a community day hospital. It will involve participant observation, clinical observations, document analysis, focus groups and interviews split in to two phases and spanning a data collection period of 19 months.

5.2 Methods

5.2.1 Data Collection

Initial Observation Phase (1)

Participants: NHS Staff, NHS volunteers, patients and relatives/carers

Timescale: up to 9 months (up to 12 hrs per week in addition to 15 hrs clinical practice).

Methods: Participant observation

Observations will be conducted within a 9 month period in order to explore and understand the organisational structure, workplace interactions and functioning between individual team members and discourse particularly in relation to frailty. This period of observations will look to give the researcher an open sense of the day to day functioning of the day hospital. Exploration will be made of the experience of staff, patients and relatives/carers within the day hospital and their understanding of these experiences. During this initial phase data will predominantly be recorded using field notes, data will be collected on both clinical (between staff and patient/relative or staff/staff) and non-clinical (anything else) interactions. Particular attention will be paid to the behaviour, language (verbal and non-verbal) and actions during interactions and the discourses around frailty. Observations and analysis of the documentation within the day hospital will also be made during this stage with an interest to the written discourse around frailty; this may include patient notes (with the patients prior written consent – see section 7), policy documentation, and paperwork in public and staff areas on display and information sheets designed for patients and/or relatives.

Data collection will be conducted as a participant observer working alongside staff as a nurse in a supernumerary role where appropriate. In order to protect patient dignity no observations will be made of intimate patient care. There is a risk that participants, both staff and patients/relatives may feel uncomfortable being observed.

This will be managed differently in the following situations:

- **Day Hospital Staff and Volunteers** – all Day Hospital staff and volunteers at CDH will be invited to take part in the study via a Phase 1 Participant information sheet (PIS) (Appendix 4 or Appendix 5). The chief investigator will attend staff meetings to talk about the study and also send an email regarding the study via the trust email system as all members of staff also have access to this. All staff who would like to participate in the study will be consented as outlined in section 7 of this protocol. For any member of staff/volunteer who does not want to participate, the chief investigator will not include them in any field notes from observed interactions. All staff and volunteers will be explicitly told that their inclusion is voluntary and this will also be documented in the PIS and consent form. All new staff will be given this information and offered the opportunity to participate and consent in the same manner.

  Patients and relatives - Phase 1 - During general observation of the day to day running of the communal areas or nurse/therapy office this will be managed by offering an ‘opt out’ system. Six A3 sized Study Posters will be placed in public areas of the day hospital where patients, relatives and staff will enter explaining that a research study is running and an overview of the study (Appendix 6), the posters are designed so that they provide information about the study, that there is observations and what the data may be used for without overloading the reader with too much detail. The poster has the researcher’s number and contact details if they need further information. The poster is designed with the patients and relatives readability in mind and therefore has large black text on a yellow background. The poster was reviewed by staff within the Day Hospital who suggested that the title of the study and the words “The research is voluntary” be highlighted in a different colour. These changes were made accordingly. A4 versions of the study poster will also be placed on the tables in the patients waiting area. A brief sentence stating that the Day Hospital is participating in an observational study will also be on the initial appointment letter for every patient. Every patient that comes to the Day Hospital has an initial assessment carried out by an experienced member of the multidisciplinary team, at each assessment the patient will be informed that the study is running, and given an A5 version of the study poster to take away with them and informed about the opt out system. If they would like to opt-out then they will be asked to sign the opt – out consent form (Appendix 7). During individual or group interactions i.e. individual patients treatment sessions or assessments, patient teaching sessions or group exercise sessions verbal consent will be gained for the researcher to be observing as part of a research study, it will be ensured that people who do not want to take part are not included in the field notes following an interaction or observation. Data will be transcribed away from the specific interaction immediately after the observation has occurred, any interaction observed where one party has opted out of participating will not be transcribed.

Development and Feedback Phase (2)

Participants: NHS Staff, NHS Volunteers, patients and relatives

Timescale: 10 months

Methods: participant observation and focus groups

During the second phase the researcher will continue to carry out participant observations as outlined in phase one. As time progresses the focus of these observations will be informed by the initial analysis of phase one and the emerging concepts of phase two.

The second phase will also consist of 4 separate focus groups involving patients, relatives/carers, day hospital staff and volunteers. The construct of these groupings were made following consultation with PPI who advised on having separate patient and relatives groups. The focus of the groups will be on the topic of identity in relation to frailty. The development of the topic guide for the groups will be an organic process informed by the initial analysis and identified concepts in phase one but will also have a focus on which aspects positively underpin cultural identity in relation to frailty within CDH. Focus group participants will collaboratively discuss, review and feedback on data collected in Phase one and identify cultural underpinnings of how identity is understood within the day hospital and how this understanding may support a positive sense of self.

Recruitment to focus groups:

a) *Patients and relatives*

Patients who meet the inclusion criteria (see section 7.1.1) will be informed about the focus group by staff members on their treatment teams and if interested given a Phase 2 participants information sheet (Appendix 10). The potential participant will be contacted by the chief investigator at least 24 hours after the PIS has been given in order to answer any questions they have regarding the study. If the potential participant agrees to take part the researcher will post a letter of invitation to attend the focus group stating the time and place of the group and a copy of the appropriate consent form for them to complete and return on the day. The researcher will also offer a courtesy phone call within the week prior to the focus group to clarify any queries.

Those patients who have consented to take part in the study will be asked if they would like their relative/carer to participate as well. If so the patient will be given the relative participant information sheet (Appendix 11) to give to their relative and the chief investigator will follow this up with a phone call to the patient between 1 and 7 days later. If the relative would like to participate the chief investigator will contact them directly and answer any questions.

b) ***NHS Staff and Volunteers***

Staff and volunteers will be informed about the focus group by the chief investigator and if interested given a Phase 2 PIS (Appendix 8 or Appendix 9), the potential participant will be contacted by the researcher at least 24 hours after the PIS has been given in order to answer any questions they have regarding the study. If the potential participant agrees to take part the researcher will give them a letter of invitation to attend the focus group stating the time and place of the group (Appendix 12) and a copy of the appropriate consent form for them to complete and return on the day. The researcher will also offer a courtesy phone call or speak to the participant within the Day Hospital, the week prior to the focus group, to clarify any queries.

Focus group (all groups)

The groups will consist of up 10 participants and will be held in a private meeting room in the hospital. Written informed consent will be obtained prior to the meeting for the data to be included in the study and for the session to be recorded (please see section 7 for a detailed consent process). A mobile audio recording device will be used to record the session. At the beginning of the meeting the researcher will facilitate the group to agree ground rules for the discussion. The topics for discussion will be identified in phase 1 and will be presented to the group via topic prompt cards and a flip chart will be used to capture responses which have been raised and key themes will be summarised and agreed with the group at the end of the meeting. Participants will be thanked for their contribution and asked if they would like summary report of findings, if they do, this will be sent to them when completed.

5.2.2 Data analysis

An iterative process where cultural concepts that arise from emersion of the researcher within the day hospital environment, will form the basis of the data analysis for this project. All data will be transcribed and anonymised by the chief investigator and analysed using thematic analysis (Braun and Clarke 2006.

NVivo, a Qualitative Data Analysis (QDA) computer software package for qualitative data coding will be utilised to;

- Manage data – including observation field notes, anonymised data files from focus groups and interviews, rough notes and developing ideas jotted into

memos, information about data sources and conceptual maps of what is going on in the data.
- Manage ideas – to organize conceptual and theoretical knowledge generated during the study as well as having the ability to link this to the data and memos that support it.
- Query data – to be able to question the data in order to support the structure of a coding system.
- Visualize data
- Report from the data

Phase 1) to understand the discursive and behavioural processes which contribute to the identities of frail older people within the day hospital

- Data from the observations and reviews of written literature within the day hospital will be collated as anonymised field notes.
- After a specific interaction or period of observation the researcher will collate field notes and transcribe them as a memo into NVivo. The field notes will use pseudonyms to protect confidentiality and describe the setting, order of activities, relevant back ground information and direct quotes in order to replicate the observed process/interaction.
- The feelings, thoughts and analysis of the understanding of the situation will also be annotated on to the text in order to link the data with the researchers notes regarding key issues and reflective thoughts about the observation.

Phase 2) to understand how the processes linked with construction of identity in relation to frailty impacts upon engagement in services,

- Anonymised focus group data will be transcribed verbatim and imported into NVivo for coding and analysis.
- Each focus group will be analysed separately
- Similarities and differences between the focus groups will be identified
- Each interview will be analysed separately
- Similarities and differences in the interviews will be identified
- Key themes identified from the focus groups and interviews will be compared and contrasted with the themes identified through the observations to gain a rich overview of the processes involved.

To ensure that the data remains relevant and accurate to the participant's data analysis will occur concurrently with the data collection during all phases. Data from the continuing observations and focus groups will be fed in to the on-going thematic analysis.

6 STUDY SETTING

6.1 Study Site

[redacted] towns on the south coast of England. Their combined populations are estimated to be just over 240,000 with the percentage of those aged over 65 ranging from 17.9-31.1% well above the 17.7% national average for the UK (ONS 2015, Bournemouth Gov 2017). [redacted] Day Hospital is part of the Medical Care Group of [redacted] Hospitals NHS Foundations Trust. The Trust provides healthcare for a catchment population of around 550,000, which rises significantly during the summer months due to the areas popularity as a tourist location. Some specialist services cover a wider catchment area, including Poole, the Purbecks and South Wiltshire.

Core services are provided to patients on both the Bournemouth and [redacted] sites which are approximately three miles apart. The [redacted] site has been largely redeveloped over the last few years and, with the exception of the Macmillan unit, is now an outpatient site with a focus on rehabilitation. Situated on the [redacted] site the Day Hospital provides specialist treatment and expertise in rehabilitation predominantly for older people.

The Day Hospital describes itself as

"A highly motivated multidisciplinary team, expert in older person's rehabilitation care.
Providing a holistic approach that supports and empowers patients to achieve independent and fulfilling lives, making it less likely that they will be admitted into hospital." ([redacted] Day Hospital 2016)

The Day hospital team is made up from specialist Geriatricians, Doctors, Occupational Therapists, Physiotherapists, Nurses and Therapy Assistants specialising in rehabilitation of the older person. Patients are referred to the service from a variety of places including the main inpatient hospital, GP, Social Services, District Nurse, Community Matron, Community Rehabilitation Services and Virtual ward/Community MDT's.

The Day Hospital is an appropriate study site as they see a high number of patients living with frailty from the local area. The vast array of ways that patients can be referred to the service also means that the chief investigator will have access to patients at different stages in their healthcare journey i.e. after an acute illness or those needing on going community input. This means that the patients and staff within the day hospital will be well placed to robustly answer the research questions.

6.2 Access to site.

Initial support for the study has been gained from the Day Hospital Senior lead and management team, and Consultant physician in medicine for the elderly within the trust.

7 CONSENT

7.1 Consent

Building trusted researcher-participant relationships is an important aspect to ethnographic research. Ethnographic research can be seen as a process rather than a single event and as such the process of informed consent may also be dynamic and evolving throughout the life of the research. The consent for this project has been carefully considered and gives regard to the Health Research Authority consent and participation guidance (HRA 2015), the Ethical Guidelines for good research practice (2011) and the Association of Social Anthropologists of the UK and the Commonwealth (ASA). According to the ASA participant observation should be based on two key principles:

"1. Participants should be made aware of the presence and purpose of the researcher whenever reasonably practicable. Researchers should inform participants of their research in the most appropriate way depending on the context of the research.

2. Field notes (and other forms of personal data) are predominantly private barring legal exceptions. This is the most important way in which confidentiality and the anonymity of subjects is ensured. Anthropologists have a duty to protect all original records of their research from unauthorised access. They also have a duty to ensure that nothing that they publish or otherwise make public, through textual or audio-visual media, would permit identification of individuals that would put their welfare or security at risk" (ASA 2011).

To adhere to the above guidelines consent for the study will be managed in the following way.

Phase 1 – Staff and Volunteers

All staff will be informed of the study via ward meetings and the trust email system to which all staff have access. The volunteers, who may not have access to the email system, will be informed of the study by the chief investigator. Study posters will also be placed around the Day Hospital in prominent places that staff and volunteers would regularly access. Staff and volunteers will be fully informed of the research aims, potential benefits and harm via PIS (Appendix 4 and Appendix 5). Potential participants will be given a minimum of 24 hours to consent to take part and will have the contact details of the chief investigator in order to answer any questions. All staff and volunteers who agree to take part will be asked to complete a written consent form (Appendix 4 and Appendix 5). The chief investigator will keep a log of those who have consented on a password protected NHS server in order to ensure that those who have not consented are not included in any field notes from this observation phase. The Day Hospital manager will inform the chief investigator of any new staff who will also have the opportunity to participate in the study following the recruitment process outlined.

Phase 1 – Patients and relatives.
The chief investigator recognises that written informed consent is preferred however there may be times, due to nature of the study methodology that during periods of the phase 1 initial observation, gaining such consent may not be conducive or possible. An important element of ethnography is building participant observer trust, the chief investigator recognises that informed consent might not be possible if for example gaining such consent would change the behaviour of those being studied and would therefore distort the data. During this phase patients and relatives will be informed of the study via Study posters (Appendix 6) which will be displayed in all communal areas. All new patients will also be given an A5 copy of the study poster at their initial assessment where an experienced member of the multidisciplinary team will explain the Opt out system. Patients and their relatives/carers will be offered the opportunity to opt out of the research by informing a member of staff who will inform the chief investigator or by contacting the chief investigator themselves whose contact details will be on the study poster. Any patient or relative who chooses to opt-out will be asked to complete an opt-out consent form (Appendix 7). Any observed interactions of people who have opted out will not be documented using field notes.

The consideration of this aspect of the consent process was reviewed and approved by the PPI group.

Phase 2
Patients, relatives/carers, staff and volunteers will be recruited to the phase 2 focus groups as outlined in section 5.2.1 of this protocol. All participants will be given a minimum of 24 hours to consider taking part. The chief investigator will answer any questions people may have regarding their participation.

7.1.1 Anonymity

The identity of anyone involved in the research activity will be anonymised using a pseudonym method. This will apply to both those who have given verbal and/or written consent and to those where it is impractical or inappropriate to gain informed consent i.e. general observations of communal areas will be protected by the researcher using these criteria;

- All data will be fully anonymised with individuals being assigned a pseudonym according to participant group, for example ‘Jane’ staff.
- If contact details are known they will be stored separately to the data on a password protected NHS server and deleted at the end of the study.
- Only the chief investigator will have access to personal contact details.

In any publication the name of the Hospital trust will also be changed to a ‘Day Hospital in the South of England’ in order to preserve confidentiality.

7.1.1 Eligibility Criteria

The older patient with frailty - Frailty criteria. Rockwood (2005) Clinical Frailty scale.

The gold standard for the management of frailty in older people is the process of care known as Comprehensive Geriatric Assessment (CGA) (British Geriatrics Society 2014). Within [redacted] Day Hospital a CGA is carried out on all patients as part of their initial assessment. It involves a multidimensional, interdisciplinary assessment of the patient by one or more healthcare professionals specialising in geriatric care.

The CGA gives a framework for the planning and delivery of interventions which address relevant and appropriate issues for an individual patient. Due to the comprehensive nature of the CGA it will be possible to use the Rockwood Clinical Frailty scale (CFS) (CFS 2009) to demonstrate the level of frailty of the individual.

The CFS was developed as a measurement tool for frailty in an outpatient setting (Rockwood et al 2005). It is felt that the CFS is the most appropriate measurement to use as it can be completed based on routine assessments already completed as part of the patients journey within the day hospital and therefore there is no need for additional intervention for them (See Appendix 13).

The Day Hospital Team

For the purpose of this study the Day Hospital team will be classed as any of the below members of staff, full, part time or from the staffing bank who are based within the Day Hospital. It will not include auxiliary services that may remote in to the Day Hospital from other parts of the trust or community teams such as phlebotomists, housekeeping, social workers or x-ray staff.

Included roles will be:

- Clinical Leaders/Management Staff
- Doctors
- Nurses
- Physiotherapists
- Occupational therapists
- Health care assistants
- Therapy assistants
- Administrative staff
- Transport staff
- Volunteers

7.1.2 Inclusion criteria

Phase 1

As the aim of the observational phase is to explore and understand the organisational structure, workplace interactions and discourses of all those who:

a) Work as part of the day hospital team
b) Attend the day hospital as a patient
c) Work as part of the voluntary team at the day hospital
d) Attend the day hospital as a relative or a carer for a patient in current treatment

will be included within the observational phase.

Phase 2

Patient's inclusion

- Patients currently receiving treatment within [redacted] Day Hospital
- Patients with a Clinical frailty scale score of 5 or above
- Patients aged over 65
- Male and female
- Any ethnicity

Relatives/carers inclusion

- Relative or carer of a patient who meets the above patient inclusion criteria and has agreed for their relative/carer to take part in the study.

Staff inclusion

- Members of the Day Hospital

Volunteer inclusion

All volunteers at [redacted] day hospital.

7.1.3 Exclusion criteria

Phase 1

Exclusions to this phase will be;

a) anyone of the above 4 groups who has chosen to opt-out of this phase
b) Any other person who works for the trust but not directly as part of the day hospital staff/volunteers. Such as phlebotomists, porters, cleaners, x ray staff.

Phase 2

Patient's exclusion

- Patients with a Clinical frailty scale score of 4 or below
- Patients aged under 65
- Patients unable to participate in group discussions due to cognitive deficits which would likely cause distress to the patient or members of the group.
- Those unwilling to participate.
- Lacks capacity to consent for themselves

Relatives/carers exclusion

- Relative or carer of a patient who meets the above patient exclusion criteria
- Relative or carer of a patient who has declined permission for them to be contacted.

Staff exclusion

- Any member of staff who declines participation.

Volunteer exclusion

- Any volunteer who declines to participate.

7.2 Sampling

7.2.1 Sampling technique

Phase 1

The sampling technique used in phase 1 is purposeful maximum variation sampling. Observations will be made of those who meet the criteria in section 7.1.2 in order to view a broad spectrum of people across the study topic area.

Phase 2

The sampling technique used in phase 2 focus groups is purposeful according to the criteria outlined in section 7.1.2.

7.2.2 Size of sample

Within [redacted] Day Hospital there are currently;

- 47 members of staff
- 8 volunteers

Approximately 50 patients are seen per day within the Day hospital either as individuals or within a number of groups which are run throughout the week. These include balance and OTAGO balance groups, Parkinson’s disease groups and Stroke education groups.

8 ETHICAL AND REGULATORY CONSIDERATIONS

The discourses around the topics of both identity and aging can be emotive and need to be managed with sensitivity and awareness of this. When research is carried out in a healthcare setting there is a risk that potential participants may feel obliged to take part in the research or concerned that their care may be affected if they decline to participate. Any participation in the project will be carried out in a fully informed and consented manner. Prior to the start of the project it will be subjected to NHS Health Research Authority, Hospital trust research and development and Bournemouth University approval to ensure that the interests of the participants are foremost. As a registered nurse the Chief Investigator is also bound by the Nursing and Midwifery Code of conduct (2015) to practise effectively, preserve safety and promote professionalism and trust.

8.1 Assessment and management of risk

Risk of injury: There is a low but potential risk of injury while working and collecting data in the hospital environment as I will be working in an environment with other people and one which I am used to working in. The researcher has an honorary contract with The [redacted] hospital NHS foundation trust which means that she will be covered through the Health and Safety at work Act (1974). She will also complete the local trust health and safety training within the day hospital.

Reportable practice: As a registered nurse the chief investigator has a legal and professional duty of care to ensure the reasonable foreseeable safety of patients and public (NMC 2015). During the study there is a possibility that unsafe practice may be observed or discussed in an interview, If I am informed of or witness practice that would be deemed reportable i.e. Malpractice, patient safety, financial impropriety, or any other serious risks to patients, public or staff, I would follow the trust policy reporting procedure. The participant study information sheets inform the participants of the researcher’s obligation to report any unsafe practices that may be raised during the study.

Emotional distress to participants: It is possible that due to the nature of the discussions surrounding identity, whilst participating in an interview or group discussion participants may become upset or distressed. The Chief investigator is a senior registered nurse with over 11 years’ experience of working with older people, and has vast experience of research interviews and discussing sensitive topics. Every effort will be made to reduce the chance of distress by approaching the interviews in a humanised way and using sensitive questioning. If for any reason the participant does become distressed at any point they will be offered the opportunity to pause the interview/group session and restart it when they feel they can, at a later time or not at all. If the participant would like any information for further support organisations in specific areas such as bereavement for example, the investigator will ask the participants permission to pass this information on to a senior occupational therapist that works within the team and has agreed to act as the point of contact. She has extensive experience working within the care of the older person and will be able to assess and provide or signpost to any further support the patient may need.

8.2 Research Ethics Committee (REC) and Governance

Before the start of the study, approval will be sought from a NHS REC for the study protocol, informed consent forms and other relevant documents e.g. advertisements.

Substantial amendments that require review by REC will not be implemented until the REC and local R&D grants a favourable opinion for the study.

All correspondence with the REC will be retained.

For NHS REC reviewed research

An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.

If the study is ended prematurely, the Chief investigator will notify the REC, including the reasons for the premature termination.

Within one year after the end of the study, the Chief investigator will submit a final report with the results, including any publications/abstracts, to the REC.

8.3 Peer review

As this study is part of a clinical academic research degree it has and will continue to under go high quality peer review both in terms of the experienced academic supervisory team at Bournemouth University [redacted]

The chief investigator attends regular academic and clinical supervision in order to review and monitor the progress of the study.

As part of the doctural process the chief investigator will also be formally monitotred and examined [redacted] at differening stages of the project, as outlines below.

- ***Initial review*** – The initial review took place in May 2017 by two independent academic members of the faculty. The chief investigator outlined her proposed study and amended some planning elements based on the feedback received. A risk assessment of health and safety and ethical issues related to the project was discussed and the future research plan and activities were agreed.

- ***Annual monitoring*** - At the end of each academic year, the progress of the projrct and the chief investogator will be reviewed. This process also includes a review of skills development and training priorities, as per the requirements of external bodies such as the Research Council, HEFCE and QAA.

- ***Transfer to higher award*** – This transfer exam ensures that the research meets the required academic standards to continue at doctural level .

- ***Final thesis submission*** - Doctoral examination

8.4 Patient & Public Involvement

The Day Hospital has an established patient and public feedback system with quarterly focus groups which patients, carers and relatives can attend. At the focus groups patients are asked to give feedback on service development ideas and suggestions for service development. As the focus groups are set up regularly the ability for patients and their relatives or carers to see the changes they are suggesting put into practice is seen.

This proposed study was presented to one of these focus groups, facilitated by the day hospital focus group co-ordinator and supported by the Trust's patient engagement coordinator. Feedback was gained on a number of areas including;

- Discussing the topic of frailty and identity, and the relevance of this for this age group.
- Discussing how best to involve people at each stage of the research, so that people feel engaged in a meaningful way.
- How they felt about the opt-out system of observational consent.
- Discussion on how they would like the focus groups in the main study to be run i.e. with patients and relatives combined or separately for example.

The feedback from the group was that the topic is important and relevant as they felt that people spoke less about how they feel about themselves as they get older.
They discussed the topic of patient observation at length and felt that this was a vitally important part of the project. It was felt that if people are not observing what is "truly" happening then there is no way to understand it and progress things. Although some members of the group felt that there wasn't a need for posters in the observation phase, they agreed collectively that some people may be upset if they were observed and there was no information at all. They decided that posters explaining that an observational study was taking place and they could opt out would be acceptable as well as a short sentence on the bottom of the appointment letter.

The sentence that was suggested was. "The day hospital is taking part in an observational research project. If you do not which to be observed please tell a member of staff".

The researcher felt that a study information sheet could also be given at the initial assessment of each patient coming to the day hospital which would outline the key aspects of the study.
In terms of the groupings of the focus groups they felt that patients and relatives should have separate groups so that it would give the opportunity for sensitive topics to be discussed around the topic of identity. There were two couples in the PPI group and they both felt that they would benefit from being given opportunity to speak freely without risk of upsetting their partner. They felt this was important as they had recognised changes in their partner's identity as they aged.
The group also reviewed the patient participation sheet, overall they felt it was clearly written and understood the information given. There was some feedback that the information was repetitive at times particularly with regard to anonymity and security. They suggested that there was one headed paragraph at the beginning covering all those items and then the document would feel easier to read.

Overall there was positive regard for the study and the group felt it was very interesting and worthwhile. They have all agreed, bar one, to continue as a patient and relative oversight group from the project and support the continuing PPI across the two phases. Following their discussion the above suggestions have been implemented within the protocol.

8.5 Regulatory Compliance

Before any patients are recruited into the study, the Chief Investigator will apply for all the appropriate NHS regulatory permissions.

8.6 Protocol compliance

Any accidental protocol deviation will be reported by the chief investigator to the supervisory team and sponsor when identified.

8.7 Data protection and patient confidentiality

The chief investigator and supervisory team will comply with the requirements of the Data Protection Act 1998 (Great Britain 1998), [redacted] Code of Good research Practice 2017 (BU 2017) and the sponsors protocols for data management with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles**.**

Any information and data gathered during the study will be held on a [redacted] password protected server. If the researcher does not have immediate access to the internet to upload data onto the server, they will use an encrypted memory stick to store data until it can be uploaded. The encrypted memory stick will be kept secure in a locked cabinet in the researcher's office when not in use.

All data will be anonymised prior to being shared with any other person other than the chief investigator. After submission of the thesis, the data will be stored securely for a period of 5 years before being disposed of according to the Sponsor's data management policy.

Archiving

In keeping with Principle 5 of the Data Protection Act 1998, data retention periods should be kept to an absolute minimum. The data will be retained for 5 years after final completion of the research. Transcribed data which has been de identified will be stored securely on a password protected personal file served by [redacted].

8.8 Indemnity

[redacted] holds Public Liability insurance to cover the legal liability of the University as Research Sponsor in the eventuality of harm to a research participant arising from management of the research by the University. This does not in any way affect an NHS Trust's responsibility for any clinical negligence on the part of its staff (including the Trust's responsibility for [redacted] employees acting in connection with their NHS honorary appointments).

[redacted] holds Professional Indemnity insurance to cover the legal liability of the University as Research Sponsor and/or as the employer of staff engaged in the research, for harm to participants arising from the design of the research, where the research protocol was designed by the University

[redacted] Public Liability and Professional Indemnity insurance policies provide an indemnity to our employees for their potential liability for harm to participants during the conduct of the research. This does not in any way affect an NHS Trust's responsibility for any clinical negligence on the part of its staff (including the Trust's responsibility for [redacted] employees acting in connection with their NHS honorary appointments

8.9 Amendments

Any amendment following approval of this protocol will be notified to [redacted] R&D department to assess whether the amendments affect the NHS permissions for that site.

Amendments will be submitted to the sponsor for initial approval. If the sponsor considers an amendment to be substantial and therefore require REC approval, a valid notice of amendment will be submitted to the REC for consideration.

All amendments will be documented and tracked using the Amendment History sheet (Appendix 3).

8.10 Access to the final study dataset

The chief investigator will have access to the full data set. Any data shared with the supervisory team will be anonymised prior.

9 DISSEMINIATION POLICY

9.1 Dissemination policy

The data arising from the study will be jointly owned by the study funders Bournemouth University and [redacted]. On completion of the study the data will be analysed and presented as a thesis document to Bournemouth University.

A key outcome of this study is to ensure the outputs from the research informs practice and thereby maximise the benefit to patients and the NHS, to achieve this, in addition to giving written feedback to study participants, dissemination activities will include:

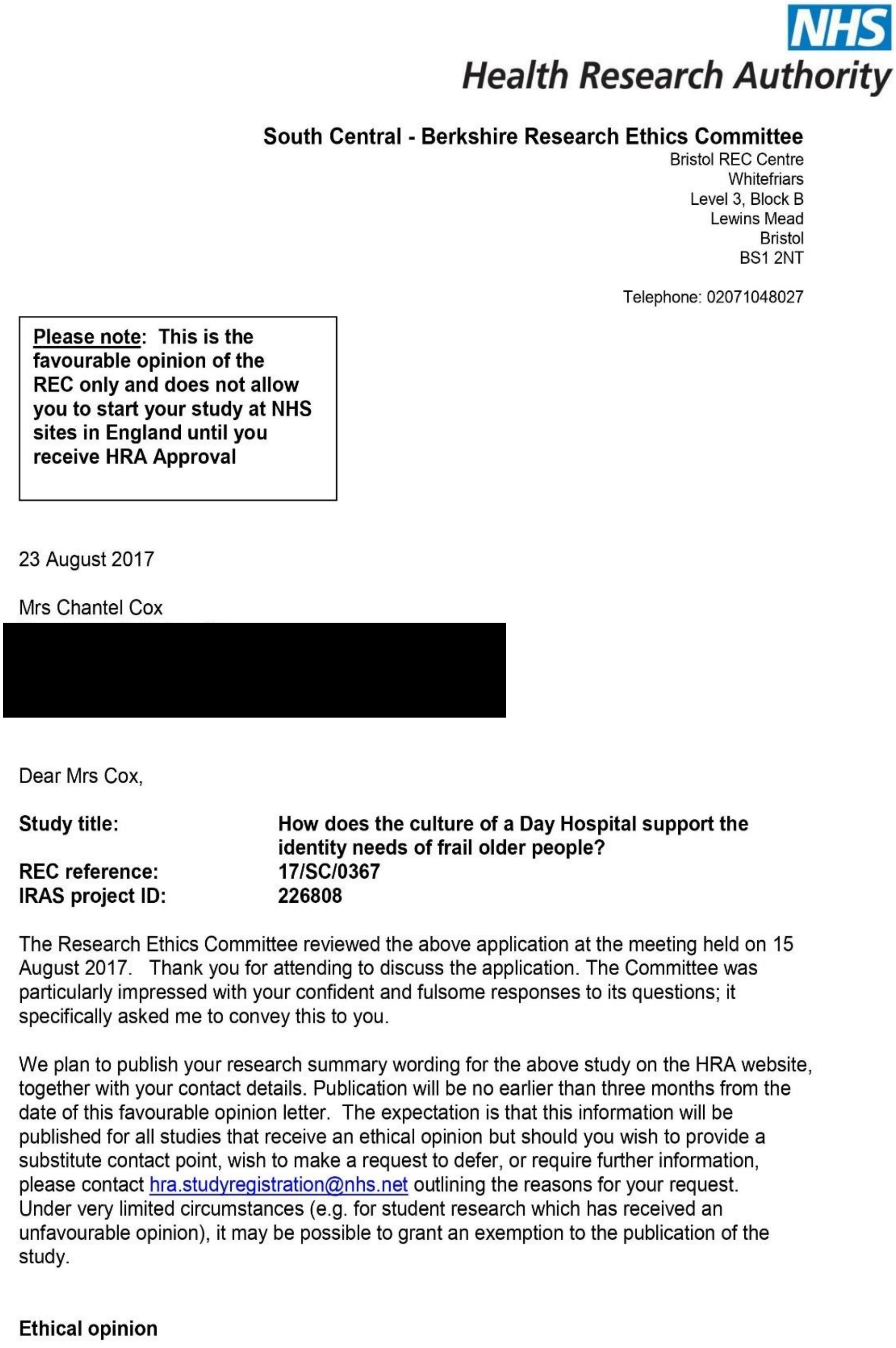
- Development and implementation of good practice guidelines for the trust

- Development of links with key special interest groups such as 'The Older Persons research collaborative'.

- Use of electronic media such as social media such as Twitter
- Publications including Full, Executive Summary and Plain English summary reports of the research, peer review journals and local NHS newsletters. The chief investigator will act as the lead author on any publications arising from the study data. The Trust will be given opportunity to review any publications before they are submitted for they are sent for peer review.

Information and Results of the study will also look to be disseminated at national and international conferences

Appendix 2 – REC ethics approval



NHS
Health Research Authority

South Central - Berkshire Research Ethics Committee
Bristol REC Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 02070148027

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

23 August 2017

Mrs Chantel Cox
[redacted]

Dear Mrs Cox,

Study title: **How does the culture of a Day Hospital support the identity needs of frail older people?**
REC reference: **17/SC/0367**
IRAS project ID: **226808**

The Research Ethics Committee reviewed the above application at the meeting held on 15 August 2017. Thank you for attending to discuss the application. The Committee was particularly impressed with your confident and fulsome responses to its questions; it specifically asked me to convey this to you.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study:

1. Please do not use the consent form for staff and volunteers; you may retain the PIS intended for use in the observation phase- it can be provided for any participant who would like more detailed information.
2. Ensure the words 'how you feel about yourself' are included in brackets after the word 'identity' in the study poster
3. Substitute the phrase 'free parking will be available' with 'reasonable travel expenses will be paid'
4. Add 'lacks the capacity to consent for themselves' as a specific exclusion criterion in the Protocol
5. Remove references to PALS in the Participant Information Sheets for the second two phases intended for use of staff and volunteers

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

[redacted]

- **Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity**

  The Committee noted that free parking would be available for participants who attend the focus groups or interviews. It asked whether any provision could be made for those participants who use public transport. It explained that it understood that some public transport may be free for participants anyway due to their age, but not all modes would be covered by this.

  Dr Board confirmed that there was money available for covering participants' travel costs.

  The Committee accepted this response and asked that this be made clear on the Patient Information Sheet.

  Dr Board and you confirmed that this change would be made.

- **Informed consent process and the adequacy and completeness of participant information**

The Committee had an extensive discussion about arrangements for obtaining consent for the first phase of the study. It noted that ‘opt-out’ arrangements would be in place for patients and relatives whilst staff and volunteers would be required to opt in and sign a consent form accordingly. It was agreed that both groups should be treated similarly. Some members believed that opt out arrangements should apply to all whilst others preferred opt in for all. After lengthy discussion it was agreed that seeking formal consent would neither be practicable nor necessary given the low risk status of the project. The Committee concluded that no participant would be required to sign a consent form for the observational phase of the study; posters and summary leaflets were acceptable and available to all, furthermore the PIS that had been produced for staff could still be available for any participant wishing to gain further information.

The Committee requested details about how the patient participants who had opted out of being observed would be identified in the field.

You explained that all patients who are referred to the day hospital go through an initial assessment by an experienced clinician who decides if the patient is able to be offered rehab in the unit. The proposed research project and the opt-out system would be explained to participants at this point, the small A5 poster given to them, and some participants may wish to opt out then. You explained that it would be yourself who would be going through the opt-out process with the participants.

The Committee queried whether it would be possible for participants to opt-out via a neutral third party to reduce the likelihood of coercion. This was of particular concern with the staff and volunteer participants.

You explained that you understood the point that perhaps the participants may feel like refusing to take part in the research may affect the participant’s relationship with you, and explained that it was possible to organise for opting-out to be organised via a third party if this was something that the committee requested. You further explained that you had devised the opting-out procedure to come via yourself so that any questions that the potential participants had could be answered immediately.

The Committee acknowledged this response and agreed that the opt-out procedure could remain as it stood via you. It also asked for further clarification as to how the opt-out procedure would work. Specifically, it would like to know how those who have opted out would be dealt with in terms of the observations.

You explained that if a participant – patient, relative, staff or volunteer – had declined to participate in the study then you would not attend that particular session to conduct an observation. You added that should an opted out participant be in a patient group, you would not observe that group.

The Committee thanked you for your clarification and accepted this response.

The Committee explained that it was not content to approve the use of different consent processes for the patient/relative participants and the staff/volunteer participants for the observational phase of the study. It explained that it would prefer that all participants are treated as if they have given assumed or implied consent, and that the provision of an opt-out process is a satisfactory means for those who do not wish to take part, regardless of which type of participant they are. It understood that staff and volunteer participants may require more information about the study, as they may have concerns about how the observation may affect their employment, but that the provision of the Participant Information Sheet was sufficient, and a Consent Form was not necessary.

You thanked the Committee for their suggestion and agreed to transition to an 'opt-out' system for all types of participants.

The Committee accepted this response, and recommended that the Participant Information Sheet be made available to the patient and relative participants as well.

- **Suitability of the applicant and supporting staff**

  The Committee asked whether you would be known to potential participants at the time of recruitment. It explained that it was asking this to ascertain whether there would be any risk of pre-existing bias and if so how this would be handled.

  You explained that you have only begun working with the day hospital as a result of your PhD studies, and have not previously worked as a nurse there.

  The Committee accepted this response.

- **Suitability of supporting information**

  The Committee noted that the word 'identity' is used prominently in the study documentation but is not well defined. It asked whether you found that this word was well understood in the patient population via your Patient and Public Involvement work.

  You explained that although their understanding of the word 'identity' had not been specifically explored during the PPI meetings the study documentation, including the poster, had been very well received. You explained that you would be open to the Committee's suggestions about how better to express the concept, and that you had been working on ways to improve this yourself. You showed the Committee the poster and suggested that the words 'how you feel about yourself' could be added in brackets after the word 'identity'.

  The Committee agreed that this made the definition much clear and asked that this change be included in the poster.

  The Committee also mentioned that there were other small administrative changes it would request and that these would be communicated to the applicant in the decision letter.

  You advised you would make these changes.

- **Other general comments**

The Committee noted that the applicant had, on being invited, submitted documents for the third and final stage of the study. It had reviewed these documents and agreed they raised no ethical issues.

You thanked the Committee for reviewing the documentation.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study Poster Phase 1]	1.0	09 May 2017
Covering letter on headed paper [Covering letter]		12 July 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers and public liability sponsor letter]		18 July 2017
IRAS Application Form [IRAS_Form_05072017]		05 July 2017
IRAS Checklist XML [Checklist_16072017]		16 July 2017
Letter from funder [Funding letter]		03 July 2017
Letter from sponsor [BU Sponsorship letter]		07 June 2017
Letters of invitation to participant [Focus group invitation letter Phase 2]	1.0	15 May 2017
Other [Clinical Frailty Scale]	1.0	10 May 2017
Participant consent form [Opt Out Patient/relative/carer consent form Phase 1]	1.0	10 May 2017
Participant information sheet (PIS) [PIS and Consent form Staff Phase 1]	1.0	10 May 2017
Participant information sheet (PIS) [PIS and Consent form Volunteers Phase 1]	1.0	10 May 2017
Participant information sheet (PIS) [PIS and Consent form Staff Phase 2]	1.0	10 May 2017
Participant information sheet (PIS) [PIS and Consent form Volunteers Phase 2]	1.0	10 May 2017
Participant information sheet (PIS) [PIS and Consent form Patients Phase 2]	1.0	10 May 2017
Participant information sheet (PIS) [PIS and Consent form Relatives/Carers Phase 2]	1.0	10 May 2017
Referee's report or other scientific critique report [Initial review feedback]		
Referee's report or other scientific critique report [Initial review feedback]		07 February 2017
Research protocol or project proposal [Protocol]	1.0	15 April 2017
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		01 June 2017
Summary CV for student [Cox CV]		01 June 2017
Summary CV for supervisor (student research) [Board Supervisor CV]		01 June 2017

Summary CV for supervisor (student research) [Ellis-Hill Supervisor CV]		01 June 2017
Summary CV for supervisor (student research) [Vassallo Supervisor CV]		12 July 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Flow Chart]	1.0	15 April 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Summary]	1.0	12 July 2017

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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 procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/SC/0367	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

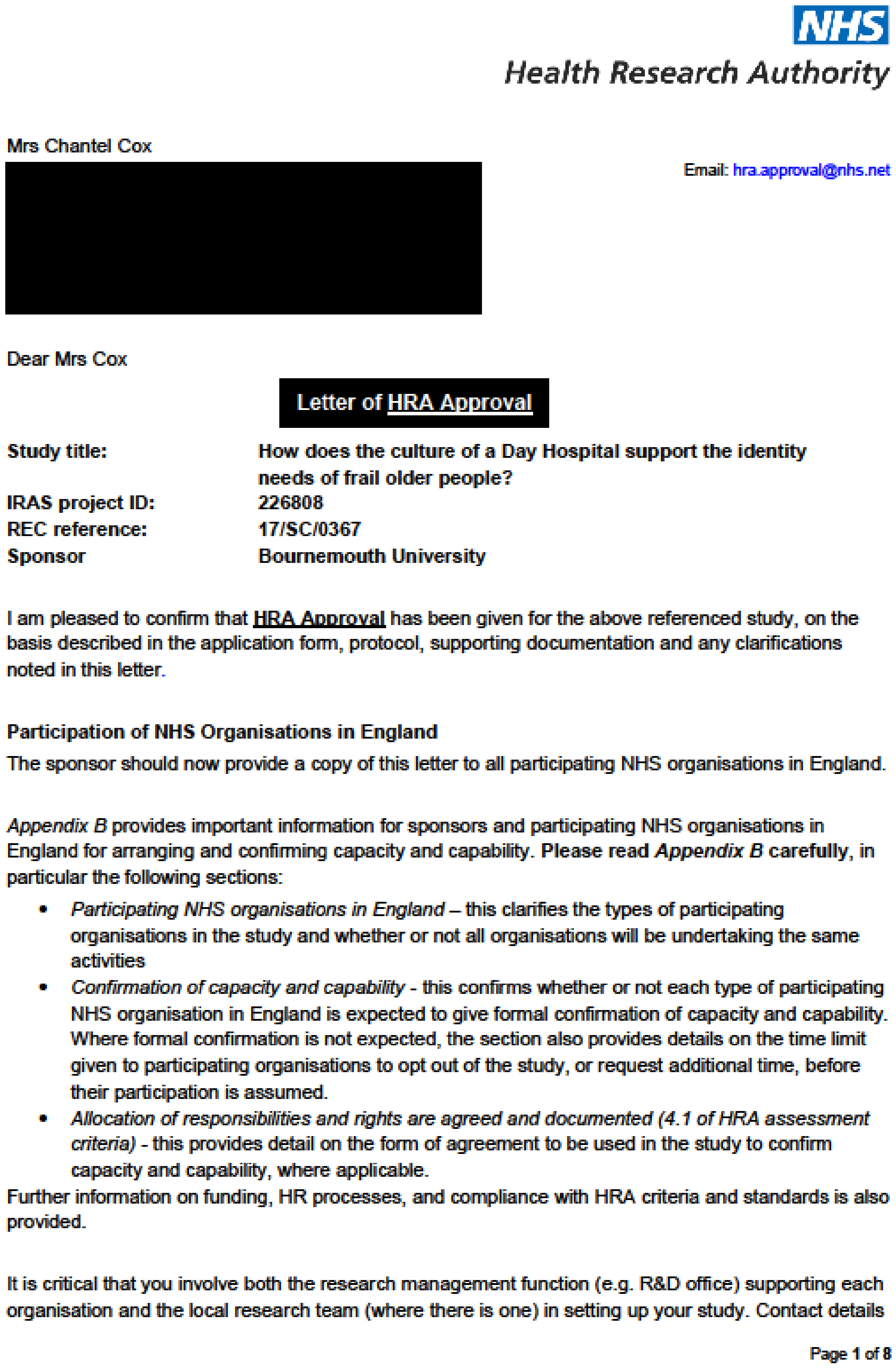
Yours sincerely

Mr David Carpenter
Chair

E-mail: nrescommittee.southcentral-berkshire@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *"After ethical review – guidance for researchers"*
Copy to:	[redacted]

Appendix 3 – HRA Approval



NHS
Health Research Authority

Mrs Chantel Cox
[redacted]

Email: hra.approval@nhs.net

Dear Mrs Cox

Letter of HRA Approval

Study title:	**How does the culture of a Day Hospital support the identity needs of frail older people?**
IRAS project ID:	**226808**
REC reference:	**17/SC/0367**
Sponsor	**Bournemouth University**

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

Appendix 4 – GDPR info sheet

GDPR INFORMATION SHEET

IDENTiFy: Supporting the identity needs of frail older people

IRAS: 226808

[redacted] University is the sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. [redacted] University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Chantel Cox.

The [redacted] NHS Foundation Trust will collect information from you and/or your medical records for this research study in accordance with our instructions.

The [redacted] will keep your name, NHS number and contact details confidential and will not pass this information to [redacted] NHS Foundation Trust will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from [redacted] University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. [redacted] will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, [NHS number] or contact details.

The [redacted] Hospital NHS Foundation Trust will keep identifiable information about you from this study for 5 years after the study has finished.

Appendix 5 – Study Poster

[redacted] Day Hospital is taking part in the observational research study: IDENTtiFy - Supporting the identity needs of frail older people

The purpose of the study is to understand how patients' needs are met in relation to their identity (how you feel about yourself) within a Day Hospital environment.

It will explore how people talk about, provide and experience care in relation to identity. A researcher will do this by observing the day to day work in the Day Hospital.

The information collected may then be used to improve future clinical practice.

The research is voluntary.

If you **do not** want to be observed please inform a member of staff or the researcher directly.

Choosing not to take part will not impact your care.

Further information please contact the researcher:

Chantel Cox

[redacted]

[redacted]

[redacted]

Version 1.1 07/09/2017

Appendix 6 – Focus group topic guide example

IDENtiFy Study Patient Focus Group Friday 11th January 2019

Welcome and thank you

Introduce myself and note taker to the group.

1. **House keeping**

- Fire tests
- Toilets
- Refreshments
- Timescales

2. **Explain the purpose of the group**

- We are doing some research looking at how it feels as people get older things that make people feel positive in the Day Hospital/

- There are no right or wrong answers everyones' experience is important and valuable so please discuss things even if you disagree as we want to hear a range of opinions.

- We would like you to do the talking, it is a group discussion rather than me asking questions but I may refer to you if we haven't heard from you in a while.

- We will anonymise the conversation before we use what you say and I would like to ask you to ensure that what is said in this room stays in this room so that people feel comfortable discussing things that are personal and may be sensitive

- If at any time you feel that you would like a break from the group please let **(the note taker on the day)** know and she will take you outside

- So that we capture everything that is said we will be recording the conversation however as I mentioned we don't identify anyone by name in the report.

Topic Guide.

What is it about the Day Hospital that makes people feel positive about themselves?

1. **Is there anything about**
    - **Environment**
    - **Staff**
    - **Volunteers**
    - **Other patients**

2. **What is the time you spend waiting like**

3. **How do people make you feel**
    - **Why**

4. **Is there anything about the day hospital that has changed the way you feel about yourself getting older?**

Appendix 7 – Participant information sheet example

PARTICIPANT INFORMATION SHEET – PATIENTS

IDENTiFy: Supporting the identity needs of frail older people

IRAS: 226808

Phase 2 – Development and feedback

You are invited to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of the study?

The purpose of this study is to understand how patients' needs are met in relation to their identity within a Day Hospital environment. It will explore how people talk about, provide and experience care in relation to identity within the Day Hospital. This information may then be used to improve future clinical practice.

Why have I been invited?

You are being invited to take part as you have been assessed and treated as a patient at [redacted] Day Hospital, are over 65 and need help with some of your day to day activities.

Do I have to take part?

Taking part in the study is entirely voluntary and if you choose not to take part this will have no negative impact to your care or treatment. If you do chose to take part you will be asked to sign a consent form. You will be free to withdraw your consent at any time during the study without giving a reason. If you withdraw from the study at a later date will have the option for us to use the information we have collected so far or we can destroy information collected up to the point it has been anonymised and processed.

What will happen to me if I decide to take part?

If you decide to take part you will be invited to attend a group discussion. The discussion group will be held within the Day Hospital and will last approximately 1 hour. There will be up to 7 other patients who have also attended the Day Hospital in the group. The group will be facilitated by the researcher and you will be invited to discuss your experiences in relation to identity, ideas that have come from the observations made in phase 1 of this study, what you think about this ideas and how we can improve care in this area.

What should I consider?

If you have some problems with your memory or taking part in group conversations you may find it difficult or distressing to take part in a group discussion. If this is the case but you would like to give your views please contact the researcher.

Will I be recorded?

If you chose to take part in the group discussions the conversations will be audio recorded and used for analysis within the study. All recordings will be anonymised and kept on a password protected secure server and stored at Bournemouth University for a minimum of 5 years.

Are there any possible disadvantages or risks from taking part?

We do not anticipate any disadvantages to you directly by taking part in the study. If you take part in the group discussion you may discuss something upsetting. You can stop the discussion at any time and the researcher will check that you are ok. If you have any ongoing issues the researcher will signpost you to further help.

What are the possible benefits of taking part?

There is no intended benefit for you individually however you may find that by taking part you will be helping us understand how identity in older people is cared for within the day hospital which will help us to improve care in the future.

Will my taking part in the study be kept confidential?

All of the information we collect about you will be kept strictly confidential. All personal data will be anonymised. Responsible members of study team may be given access to data for monitoring of the study to ensure that the research is complying with applicable regulations. Data from the study will be kept on a password protected secure network in accordance with the General Data Protection Regulations and Data Protection Act 2018.

The focus groups will focus only on your experiences and we will ask you not to discuss individual patients in order to protect confidentiality.

If any safety issues that put patients at risk are witnessed during the observations or discussed in group discussions or interviews, the researcher is obliged to report these under the Nursing and Midwifery code of conduct 2015.

Will I be reimbursed for taking part?

You will not be reimbursed for your taking part in the study, however reasonable travel expenses will be paid if you attending as part of a group discussion for the study.

What will happen if I don't want to carry on with the study?

Taking part in the study is voluntary and you may withdraw at any time up until the point that the data is anonymised without giving reason. Withdrawing will not affect the care you receive from any services. If you would like to withdraw from the study in the future you should contact the researcher or tell a member of your healthcare team. If you withdraw from the study at a later date you will have the option for us to use the information we have collected so far or we can destroy information collected up to the point it has been anonymised and processed.

What will happen to the results of this study?

This research is being carried out as part of a PhD thesis by the researcher. At the end of this study she will submit the results of the thesis to [redacted] and also for healthcare journal publication. All information used will be fully anonymous.

What if there is a problem?

The Patient Advisory Liaison Service (PALS) is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. PALS are unable to provide information about this research study.

If you wish to contact the PALS teams please telephone: [redacted]

If you wish to complain about any aspect of this study, you should contact Professor [redacted]

How have patients and the public been involved in this study?

A group of former patients and some of their relatives/carers have reviewed the study and contributed to various aspects of its design. This group will also continue to act as a patient oversight group throughout the duration of the study.

Who is organising and funding the study?

The study is jointly funded between [redacted]

Who has reviewed the study?

This study has been reviewed and given favourable opinion by [redacted]

[redacted] is the sponsor for this study based in the United Kingdom. We will be using information from you and or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. [redacted] will keep identifiable information about you for 5 years after the study has finished.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Chantel Cox or [redacted]

For Further information:

Please contact the researcher Chantel Cox  [redacted] [redacted] [redacted]	Or Supervisory Team [redacted] [redacted] [redacted]

Thank you for considering taking part.