# The impact of the transition to a care home on residents' sense of identity

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#### List of abbreviations

- SITSocial Identity TheorySCTSelf-Categorisation TheorySIPSocial Identity PerspectiveCQCCare Quality CommissionFAFramework AnalysisRECResearch Ethics CommitteeR&DResearch and Development

#### Abstract

The transition to a care home can be a difficult experience for older people, with various changes and losses, which can impact an older person's sense of identity. However, it is not clear how older people perceive and manage their sense of identity within a care home, particularly in the United Kingdom. This study aimed to explore how the transition to a care home impacted on the identities of care home residents, and how they addressed this impact. Findings were interpreted using the Social Identity Perspective (SIP), which postulates that people strive to maintain a positive identity. Identities are composed of a *personal identity* (relating to personality traits), and a *social identity* (relating to group membership). SIP can help to interpret the symbolic nature of interactions and experiences, although to date has been infrequently used in care home based research.

This study used a case study approach with qualitative methods. Cases of three care homes were purposefully sampled within Greater Manchester. Residents, relatives, and care home staff were asked to participate. Semi-structured interviews with 18 participants (nine residents; four relatives; five staff), and approximately 260 hours of observations were conducted over one year. Data were analysed using Framework Analysis.

Results revealed five overlapping themes: 1) Social comparison; 2) Frustration; 3) Independence and autonomy; 4) Personal identity vs. Care home; 5) Ageing and Changing. Overall, the transition to a care home had a negative effect on residents' identities, due to organisational restrictions and associations with cognitively impaired older people. In order to forge a positive identity, residents without dementia aimed to distance themselves from residents with dementia, whom they perceived negatively. To achieve this distance, residents without dementia engaged in social comparison, by emphasising their comparatively superior cognitive abilities and physical independence. Symptomatic behaviours of residents with dementia also caused frustrations amongst staff and other residents. Furthermore, differing expectations of the care environment caused frustrations between residents, relatives, and staff. Most routines and restrictions made it difficult for residents to express their personalities. Although staff aimed to incorporate residents' individuality into care, they often reported feeling restricted by a lack of staffing and resources. Additionally, residents considered the physical impact of ageing to alter their established sense of identity. However, the care home further undermined residents' identities, particularly in relation to their independence and autonomy, which were important elements of their personal identities. Residents' perceptions of what counted as independence changed in light of their declining physical abilities and what they were allowed to do within the care home, in order to maintain this element of their identities.

Findings indicated that the care homes would benefit from more resources to organise more meaningful activities for residents. However, small changes to routines, such as allowing 'duvet days', also helped to support residents' identities. Recommendations for practice include the introduction of an 'identity champion' to provide guidance and support on how care home staff could make identity-relevant changes.

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#### **Chapter 1: Introduction**

#### 1.1. Overview

The transition to a care home can be a tumultuous experience for older people. They can become disconnected from important social networks, familiar daily routines and activities, and other aspects of their identity, which can consequently impair well-being (Tester *et al.*, 2004; NCHR&D, 2006; Bridges, 2007). It is therefore important to ensure that older people are receiving care that encourages the maintenance of their own identities. This thesis explores how the transition to a care home impacts residents' sense of identity, and the process of identity maintenance and construction. This chapter provides an introduction to the background of the study, including an overview of the UK context of long-term residential care for older people, and the definition of identity and the importance of this concept for care home residents.

#### 1.2. Demographics: Ageing population and aged care

The world is experiencing an ageing population (United Nations, 2013). The global older population (aged 60 or over) is expected to more than double from approximately 841 million in 2013, to over 2 billion in 2050. In the UK, there are now 11.4 million people aged 65 or over in the UK (Office for National Statistics, 2015), and the number of people aged 85 and over has increased by 30 per cent between 2005 and 2014 (Office for National Statistics, 2013). It is also estimated that approximately 76 per cent of older people will require some form of care in later life (HM Government, 2012), which can range from home-based assistive care to long-term residential and/or nursing care. Recent statistics show that there are approximately 400,000 older people in the England residing in care homes (Care Quality Commission, 2012). The definition of a care home used throughout this thesis is presented in Box 1.

People who move to care homes are older and experiencing higher levels of dependency and impairment, including dementia, than in previous years (Lievesley *et al.*, 2011). Though dementia is not an inevitable part of ageing (World Health Organisation, 2012), one in six people over the age of 80 will experience a form of it (Alzheimer's Society, 2014b). About 80 per cent of older people in care homes have dementia or another form of cognitive impairment (Alzheimer's Society, 2013). The definition of dementia used throughout this

thesis is presented in Box 2. Furthermore, in 2001, the population of care home residents aged 85 and over represented 56.5 per cent of the whole care home population, whereas in 2011 they represented 59.2 per cent of the population (Office for National Statistics, 2014). For many, the transition to a care home occurs at the nadir of physical and/or cognitive abilities, further compounded by possible anxieties about the consequences of the transition. However, over the period 2001 to 2011, the number of people aged 65 and over living in care homes in England and Wales remained relatively stable (Office for National Statistics, 2014). This may be due to the fact that older people are able to maintain their independence for longer. Public policy and government schemes have tended to focus on keeping older people in their homes, by helping them to remain independent (Department for Communities and Local Government and Hopkins, 2013).

Care homes remain an important housing and care option for older people who require extra support and care (Office for National Statistics, 2014). However, reports suggest that funding cuts to local government budgets forces councils to increase the eligibility threshold to receive care and support, making it difficult for some older people who want to move to a care home to meet the necessary criteria (BBC News, 2013). Furthermore, care home care can be expensive. On average, the weekly cost of residential care in England is £550, and £728 for nursing home care (Laing and Buisson, 2014). Families may decide against formal residential care due to financial reasons including restrictions in financial assistance from local councils. In 2013, Health Secretary Jeremy Hunt promised to reform social care by capping the amount people would have to pay for their care, and raising the means-tested threshold for care home care to £123,000 (BBC News, 2013). However, these plans have been delayed until 2020 (Helm and Bachelor, 2015).

#### Box 1. Definition of a care home

#### Care home: definition

The term 'care home' is a catchall term that refers to long-term residential care with and without nursing care. Residential homes typically offer accommodation and personal care, including washing and dressing; whereas nursing homes offer these services in addition to more advanced nursing care (British Geriatrics Society, 2011). Care homes can also be dual-registered, offering both residential and nursing care, depending on individual need. There is often overlap between the clinical needs of these populations with some residential homes providing a degree of nursing care (British Geriatrics Society, 2011).

Care homes can also vary in terms of ownership (e.g. not-for-profit, or owned by a large company), structure or type (e.g. whether a converted home, or purpose-built as a care home), and categories of residents that care is provided for (such as those specialising in dementia or learning disabilities). Nonetheless, throughout the literature, the term 'care home' has been used to refer to both residential and nursing homes, despite their heterogeneity (e.g. NCHR&D, 2006; British Geriatrics Society, 2011; Office for National Statistics, 2014), and shall be used in the same way in this thesis.

#### Box 2. Definition of dementia

#### **Dementia:** definition

'Dementia' is a syndrome that describes a broad set of symptoms, including memory loss, impaired reasoning and language difficulties (Alzheimer's Society, 2014b). There are over 100 forms of dementia, caused by different diseases. The most common forms of dementia are Alzheimer's disease and vascular dementia.

It is common for people with dementia to experience altered mood and behaviour, excessive walking around or wandering, aggression, repetitive questioning and shouting (Banerjee, 2009;Alzheimer's Society, 2014a). For the purposes of this thesis, the word 'dementia' will be used as shorthand for all types of dementia.

#### **1.3.** Transition to a care home

There is a lot of negativity surrounding care homes, and living in a care home (O'May, 2007). The majority of older people wish to remain in their own homes (Wanless *et al.*, 2006), and moving to long-term care is often seen as the last resort (Oldman and Quilgars, 1999). Further, findings from a YouGov poll showed that 70 per cent of adults stated that they would be scared of moving to a care home (Quince, 2013). The transition to care home life is associated with a threat to quality of life and a loss of independence (Starck, 1992). Such negative perceptions of care homes are further compounded by scandals in the media, including Orchid View, where residents suffered neglect and abuse at the hands of care home staff (Brindle, 2013; Slater, 2015; Taylor, 2015). Also, issues with understaffing are well-documented, with one in five care homes with nursing lacking a sufficient number of staff on duty in order to ensure good quality care (Care Quality Commission, 2014).

The transition to a care home is not only a particularly emotional time for older people and their families, but also a significant life event and a critical period for new residents (Heliker and Scholler-Jaquish, 2006). Newly admitted residents have a tendency to withdraw socially, become anxious and experience changes in their sleeping and eating patterns (Brooke, 1989). Previous literature has suggested that the transition to a care home can undermine a resident's identity (Peace *et al.*, 1997; Bridges, 2007; Froggatt *et al.*, 2009), which can in turn impact his or her well-being or self-esteem (Tajfel and Turner, 1979; Phinney *et al.*, 1997; McKee *et al.*, 1999; Howarth, 2002). Given the significance of the transition to a care home, it is

important that it go smoothly by including the views of all the stakeholders involved (NCHR&D, 2006).

The move to long-term care can be planned or unplanned, with the latter likely to occur in the event of an emergency. Older people may transition to a care home from their own homes or other forms of care, such as hospital, assisted living facility or the home of a family member. Davies and Nolan (2003) suggested that there is some variability in how involved an older person is in the decision to move to a care home. Some have a carefully planned and informed experience to determine whether the move to a care home is appropriate, and if so, to which facility (Davies and Nolan, 2003). A more successful adjustment to care is associated with a planned admission, rather than unplanned (Wilson, 1997; Walker and McNamara, 2013), and having been involved in the decision-making process, rather than having less control, or no control at all (Davies and Nolan, 2003). The period surrounding the transition to long-term care is also of particular importance for care home staff to identify and address health issues, and assist in residents' adjustment to the facility.

It is necessary to define identity, before continuing the discussion about how identity is influenced within the care home.

#### 1.4. What is 'identity'?: Understanding the Social Identity Perspective

How identity is defined or conceptualised is a contested issue and multiple definitions have been proposed. For instance, Erikson (1959) explores the psychosocial development of a person's ego identity throughout different life stages. Other authors have explored a hierarchy of identities (Stryker, 1980), or levels of self, specifically exploring Alzheimer's disease (Sabat and Harré, 1992; Sabat and Collins, 1999; Beard, 2004). Identity has been defined in terms of roles (Cohen-Mansfield *et al.*, 2000, 2006), or embodiment (Kontos, 2004). Petzold also suggests that identity is based on five pillars: the body and mind; relationships; work and accomplishments; material security; and values (Riedl *et al.*, 2013). These definitions are equally valid conceptualisations and give emphasis to different foci of the concepts of self and identity. However, some largely focus on older people with dementia (Sabat and Harré, 1992;Cohen-Mansfield *et al.*, 2000; Kontos, 2004; Cohen-Mansfield *et al.*, 2006), consider identity as a linear process (Erikson, 1959), or focus on a particular element of a person's identity (Cohen-Mansfield *et al.*, 2000; Cohen-Mansfield *et al.*, 2006).

To get a general understanding of identity and the process of identity management within a care home, a broader non-dementia specific conceptualisation of identity was considered useful. An alternative conceptualisation of identity comes from the Social Identity Perspective (SIP), which has been a prominent approach within social psychology. SIP highlights the reciprocal nature of interaction within a particular social context, as well as the cognitive processes involved in the management of identity and intergroup interactions. SIP has been used in other research based in care homes, and has demonstrated that SIP can develop our understanding of this social environment (Haslam *et al.*, 2009; Knight *et al.*, 2010). This perspective can be useful within the context of the care home to explore how identity is challenged and managed on a daily basis through interaction with other groups and individuals. The next section describes SIP in more detail, and explicates its usefulness for the current study.

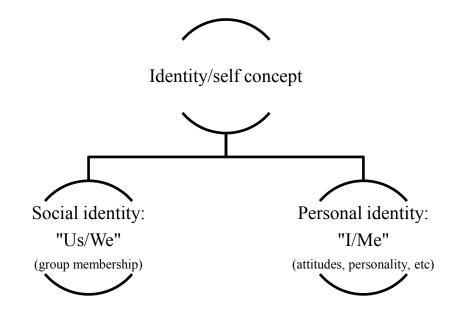
Social Identity Perspective arose from combining Social Identity Theory (SIT) (Tajfel and Turner, 1979; Tajfel, 1982) and Self-Categorisation Theory (SCT) (Turner, 1982; Turner, 1985; Turner and Oakes, 1986; Turner et al., 1987). These are two interrelated approaches that address identity whilst incorporating the importance of social and contextual issues in an attempt to compensate for the overly individualistic approaches within social psychology (Turner and Oakes, 1986); something that many other theories of identity fail to address. Social Identity Theory is perhaps best known in relation to work on group differences and conflict, such as in the "Klee and Kandinsky" experiment (Tajfel and Turner, 1979). Such experiments demonstrated the importance of group membership as a determinant for individual behaviour, even for seemingly unimportant groups, like those based on a preference for the paintings of particular artists. Making the mere distinction between 'us' and 'them' is enough to change how people saw one another, and consequently influence their behaviour (Tajfel and Wilkes, 1963). People enhance similarities between those in the same group, and enhance their differences with those in another group, the 'out-group'. Social Identity Theory can help to explain our tendency to discriminate and provoke conflict between social groups, but not why certain groups are used as a basis for one's identity or the meaning we give to these distinctions. Self-Categorisation Theory (Turner, 1985; Turner et al., 1987; Turner et al., 1994a) elaborates intragroup processes, to build upon SIT and address some of its criticisms. They shall therefore be discussed in tandem throughout this thesis, only drawing distinctions between the two theories when necessary.

Overall, SIP is broadly influenced by symbolic interactionsim, which focuses on the exchange of information between people or groups through interaction. Mead (1934), a prominent symbolic interactionist, focussed on the relational foundations of identity and self-concept<sup>1</sup> through social interaction and social categories, thus emphasising the exterior world in the development of the self, i.e. the importance of the 'Other' in interaction. SIP is primarily concerned with how social categorisation and its subsequent internalisation can impact social behaviour (McLean and Syed, 2014). Though SIP is more explicitly linked to cognitive views on categorisation and intergroup behaviour, SIP can still be considered to be a descendant of Mead's emphasis on social interaction (McLean and Syed, 2014). The reasons for this being that the cognitive processes outlined in SIP (discussed further below) are heavily context dependent and reliant on interpersonal and intergroup conflict, it is still a relevant approach to understanding group processes and psychological mechanisms to promote a positive identity. Therefore, a person's self-concept is not just a solitary, individual affair; rather, identity is cognitive *and* social.

The Social Identity Perspective draws a distinction between two interrelated levels of an individual's self-concept, or their overall identity: social identity and personal identity; as illustrated in Figure 1. The term 'social identity' is "that part of the individual's self-concept which derives from their knowledge of their membership of a social group (or groups) together with the value and emotional significance of that membership" (Tajfel, 1981: 225) and the shared sense of identification with other members of the same group, or 'in-group'. Personal identity refers to the idiosyncratic, unique characteristics of an individual including personality traits, physical attributes, culture, and attitudes (Tajfel and Turner, 1979; Turner, 1982; Hogg and Abrams, 1988; Reicher *et al.*, 2010). The elements of personal identity are not explored in as much depth with either Social Identity Theory or Self-Categorisation Theory.

<sup>&</sup>lt;sup>1</sup> The terms "self-concept" and "identity" are often used interchangeably in the literature, as shall be the case throughout the thesis.

#### Figure 1. The structure of self-concept. Adapted from Hogg and Abrams (1988)



According to SIP, the concept of identity is not a fixed mental structure, but is comparatively fluid and context-dependent. There are an innumerable amount of identities an individual can access, and each is not necessarily mutually exclusive, and can even be contradictory (Hogg and Abrams, 1988). Different identities will become salient depending on the context (Turner, 1982; Hogg and Abrams, 1988; Oakes, *et al.*, 1994). For example, older people may feel their age-related identity is more salient when surrounded by other older people, but their religious social identity may be salient when in church. Furthermore, the concepts of a 'social' or 'personal' identity are not necessarily mutually exclusive; identity is a social process that incorporates individuality (Hockey and James, 2003). Identity construction is also an ongoing process, which continues across the life course, and in response to major life events or transitions (Giddens, 1991; Billington *et al.*, 1998; Hockey and James, 2003).

The transition to a care home often involves leaving, or diminished contact with, important individuals and social groups (NCHR&D, 2006; Bridges, 2007) that had been part of an older person's identity, thus reducing their saliency in favour of another, more salient, group. This could also be applied to the experience of ageing in general, with diminished saliency of certain groups due to frailty or death. But the new context of the care home further compounds this issue with the introduction of new sources of interaction (such as members of staff and other residents), which may or may not perceive the individual resident in a manner that reflects his or her pre-established identities.

Categorisation of people or objects helps us to make sense of the world. Self-Categorisation Theory enables us to understand our perception of collections of stimuli, and the consequences of perceiving those collections in a particular way. Membership to a group can be imposed on a person, but they will not necessarily categorise themselves in that way and adopt it as their social identity (Brewer, 1991). The likelihood that we categorise ourselves or others as a certain groups depends on two processes: accessibility (also known as perceiver readiness) and fit. First, accessibility; this means that a particular social category is likely to be salient if it "...reflects a person's past experiences, present expectations, and current motives, values, goals and needs." (Turner et al., 1994: 5). For example, I have selfcategorised myself by my nationality, British, in the past. I shall use the categorisation of 'British' when in new social situations, which call for this distinction. Second; 'fit' has two aspects: comparative fit and normative fit, which are inextricably linked (Turner et al., 1987; Turner et al., 1994b). Comparative fit refers to the degree of differences or similarities between two stimuli within a particular frame of reference. Normative fit refers to the typical content of these categories, such as particular behaviours or attitudes one would expect from that category. Social groups only become 'real' social groups when they have at least one comparator (Hogg and Abrams, 1988). For instance, the concept of 'female' is only actualised through the existence of the 'male' comparator group. The concept of being a care home resident is only actualised through the existence of non-residents.

#### **1.4.1.** Stereotypes, comparisons and negative social groups

According to SIP, people have an overarching desire for a positive and secure self-concept, which is the main motivation behind the intergroup discrimination (Tajfel and Turner, 1979; Reicher *et al.*, 2010). Given the inextricable link between social identity and self-concept, membership of a particular social group can impact an individual's self-esteem. Social groups can be judged and evaluated by other groups on a variety of domains, and thus develop a higher or lower status in the eyes of others. Group members are typically aware of their status. This relates to work by Festinger (1954) on social comparison, which Tajfel Tajfel and Turner (1979) later expanded upon within SIT. According to the latter, rather than a desire for accurate self-evaluation, individuals desire self-enhancement, typically achieved through comparison with a relevant out-group (e.g. men vs. women; Labour vs. Conservative). A negative perception of a group can be a result of derogatory stereotypes associated with that

group (Tajfel and Turner, 1979) i.e. strict assumptions of the normative fit of a group. Membership in a poorly perceived social group can provoke the internalisation of a negative self-concept, (Howarth, 2002), which can lead to depressive symptoms (Kroger *et al.*, 2010). That is not to suggest that everyone who belongs to a negatively perceived social group will suffer from depression, but if an identity is salient enough and a large, salient part of a person's self-concept, it is more likely to impact self-esteem than with an identity that is less important (Hogg and Abrams, 1988). Older people, particularly care home residents, are negatively stereotyped as being frail, impaired and dependent (Butler, 1975; Cuddy *et al.*, 2005; Meyer *et al.*, 2006). It is therefore likely that older people do not wish to self-categorise as old, or as a care home resident, at the risk of being considered to be as frail in the eyes of others (Jetten *et al.*, 2011), despite their residency in a care home being a likely salient social category.

When in a negatively perceived social group, individuals may utilise a variety of strategies to enhance their self-concept (Tajfel and Turner, 1979; Tajfel, 1981; Reicher *et al.*, 2010). These depend on the malleability of the boundaries between groups, for example, people can change which sports team they support but not their age. Firstly, when boundaries are perceived as permeable, individuals can engage in **social mobility**. Members of negatively perceived ingroups can *physically* or *psychologically* leave the group, as there are a multitude of other possible social groups one could move to or focus on (Tajfel and Turner, 1979). Older individuals may not define themselves in terms of their chronological age (Montepare and Lachman, 1989; Bowling *et al.*, 2005), but can psychologically distance themselves from this and redefine themselves in terms of how old they 'feel', or focus on an entirely different social identity.

Secondly, if boundaries are perceived as impermeable, and therefore social mobility is not an option, there is **social creativity**. Group members can either: *re-frame* the negativity associated with the group, thus making a 'negative' a 'positive' (e.g. the "black is beautiful" movement in the 1960s); *change comparator dimensions* to something that makes the ingroup seem more positive; seek to *compare* themselves with a lower-status outgroup; or make *intragroup* comparisons with ingroup members who are worse off, or in terms of their personal identity, not their social identity (Turner *et al.*, 1987). For instance, in a qualitative study of mental health service-users, clients would differentiate between types of mental ill-health, distancing themselves from negative representations of more severe illnesses to

protect their identities (Foster, 2001). Thirdly, if boundaries are perceived as impermeable, but the low status of the group is considered to be illegitimate or undeserved, a group can collectively engage in **social competition**, through direct competition with the outgroup (Tajfel and Turner, 1979; Tajfel, 1981; Howarth, 2002; Reicher *et al.*, 2010; Jetten *et al.*, 2011; St. Claire and Clucas, 2012). There appears to be little research exploring the possibility that similar strategies may be used among older people who reside in care homes.

The Social Identity Perspective has been used to explore the impact of transitions on individuals' identities (Iyer *et al.*, 2009), in health and social care research (Jetten *et al.*, 2012), and to explore the effect of group-based decision-making in care homes (Knight *et al.*, 2010). However, SIP has not yet been used to explore the impact of the transition to a care home on identity, or the concept of identity in care homes in general, within the UK. Following a major transition, such as the move to care home, individuals may have to cope with the loss of existing identities, and the possibility of adopting a new identity (Iyer *et al.*, 2009). This can be even more difficult if certain social groups or traits are seen as important to a person's self-concept (Ellemers, 2003). Adopting a new identity following a transition can buffer against the negative impact of the transition (Haslam *et al.*, 2009; Jetten and Pachana, 2012), but this has not been explored in care homes. SIP can be used to explore these issues in detail, including how residents manage their identities on a daily basis, with a focus on contextualised, symbolically charged interactions. The next section discusses the concept of identity in the care home as presented in the current literature, policy, and guidelines for care homes.

#### 1.5. Identity in the care home: an overview

Living in a care home can undermine one's identity (Peace *et al.*, 1997) due to the loss of important social networks, relationships, personal routines, and belongings (Chaudhury, 2003; Bridges, 2007; Bridges *et al.*, 2010). The maintenance of identity is closely linked with well-being and self-esteem (Tajfel and Turner, 1979; Phinney *et al.*, 1997; McKee *et al.*, 1999; Howarth, 2002; Haslam *et al.*, 2009). To address this, various evidence-based policies and guidelines highlight the importance of maintaining 'personal identity' within the care home in order to promote positive well-being and quality of care (Bridges *et al.* 2007; My Home Life Cymru and Age Cymru, 2011; Nice, 2013). To achieve this, such guidelines suggest adopting person-centred care, consistent assignment of staff who appreciate the psychosocial aspects of their roles, the use of reminiscence therapies, exploring

ethnic/cultural/spiritual needs, engaging in meaningful activities (Scharf *et al.*, 2005; Nice, 2006), and allowing control over personal space, including bringing personal possessions (Bridges, 2007; My Home Life Cymru and Age Cymru, 2011).

Generally, proponents of person-centred care emphasise treating people as individuals and understanding what matters to that person, within a positive environment, in order to improve the quality of care and, subsequently, wellbeing (Brooker, 2004). This originated from Kitwood's (1997) work on personhood in dementia, and is considered to be one of the most dominant and influential opponents to the biomedicalisation of dementia care. Personhood refers to "the central attribute of being a person" (Bridges, 2007: 52), which, under the biomedical model, is considered to be lost as dementia progresses, leaving a passive 'sufferer' of the disease. However, by arguing against this determinism, focusing on the dialectical relationship between neuropathology and psychosocial environment, and ultimately seeing the person beyond the diagnosis (Kontos, 2004; McCormack, 2004), Kitwood (1997) and others recognised an enduring personhood. Focusing on the individual within the care environment led to a "paradigm shift in dementia-care" (Belloni et al., 2014: 4701), and instigated the development of person-centred care. It is one of the major principles of quality care promoted by the National Service Framework for Older People (Department of Health, 2001), and though poorly defined, is a "watchword" for good practice (Nolan et al., 2004). This is an important approach to care for residents regardless of dementia diagnosis, as the transition process, the potentially disabling environment of the care home, and being physically/cognitively frailer can diminish residents' ability to exert their individuality and sense of identity. Incorporating biographical knowledge of the individual through person-centred care can help residents to maintain their identities (Bridges, 2007; Bridges et al., 2009; My Home Life Cymru and Age Cymru, 2011).

There are a number of ways that research and guidelines suggest that care homes could support residents' identities. These include supporting residents to engage in activities that reflect current or past hobbies, or help them to engage in new, personally relevant activities. Such activities could also help the resident to form friendships with other people in the care home. Furthermore, allowing residents to bring personal possessions with them can help them feel 'at home' (Bridges, 2007; NICE, 2013), and help residents to express their personality and identity (James, 1890; Wallendorf and Arnould, 1988; Cram and Paton, 1993; Kroger and Adair, 2008; Gosling, 2009). However, a single room in a care home has been shown to

be smaller than some prison cells (Dudman, 2007), which can severely limit what an older person can keep. Many care homes are also considered to be under-funded, so often cannot afford to organise regular activities (Dudman, 2007), and studies consistently find that many care home residents spend most of their day in passive inactivity (Ice, 2002; Davies *et al.*, 2005).Therefore, despite an increased in focus of policy on the importance of preserving personal identities within care homes, there appears to be some inconsistency in whether care homes are achieving these goals.

#### 1.6. Summary

This chapter presented a description of the context of the research. The UK has an ageing population, and a growing population of older people residing in care homes with more advanced impairments, but people are reluctant to move due to negative perceptions of care homes and concerns over diminished independence. The transition to a care home can be positive if the older person is involved in the decision-making process. But the transition can also have a negative physical and emotional impact on care home residents, including the resident's identity. Policies and guidelines for care for older people focuses on promoting person-centred care through the use of biographical information about the resident's sense of identity within the care home is essential for positive adjustment and well-being. Though this is an issue that has been highlighted in previous research, policy and guidance for care homes, there is little exploration of the strategies used by older people to maintain a sense of identity on a daily basis, and their subjective experiences of the identity management process. The use of the SIP enables this exploration and offers a perspective that has been used in only a small body of care homes based research (Haslam *et al.*, 2009; Knight *et al.*, 2010).

#### **1.7. Structure of the thesis**

This thesis consists of seven chapters. Chapter Two presents a thematic review with a systematically constructed literature search of the current literature surrounding the concept of identity in care homes, including what is currently known and what is missing from the literature. Chapter Three presents the methodology, and Chapter Four the working methods used throughout the study. Chapters Five and Six explore the overall findings of the study, and Chapter Seven presents a discussion of those findings in light of the literature, including reflections on the methodology and relevance of the research for practice and further study.

#### **Chapter 2: Literature review**

#### **2.1. Introduction**

The last chapter demonstrated the background, relevance and purpose of the study. Previous research has suggested that the transition to a care home can have a potentially negative impact on residents' sense of identity. Studies have identified a relationship between identity and depression, self-esteem and declining well-being (Tajfel and Turner, 1979; Koteskey *et al.*, 1991; Phinney *et al.*, 1997). Supporting care home residents' sense of identity is therefore important in improving care for older people.

This chapter presents a systematically conducted thematic review of published studies reporting the impact of the transition to a care home on residents' sense of identity. The aim of the literature review was to unearth the current literature on the construction of identity within a care home, and to gain a deeper understanding of the impact that the transition to long-term care has on residents' sense of self, from the residents' perspectives. The methods used in the included studies will also be discussed. There are few examples of studies that include multiple stakeholder perspectives on this issue, and most solely focus on residents with dementia. Few studies explore the identity of care home residents over time, providing minimal in-depth data. Studies offered limited exploration of how residents engage in identity management on a daily basis, with little description of the strategies that care home residents use to manage their identities. The conclusions of the review are then discussed in relation to the aims of the overall study.

#### 2.2. Review question

How does the transition to a care home, and life in a care home, impact residents' identity?

#### 2.2.1. Aims and Objectives

Identify and present studies that investigate the impact of the transition to, or life in, a care home for older people.

#### 2.3. Methods

There is a diverse range of ways to approach literature reviews, which ultimately depend on the questions being asked (Snilstveit *et al.*, 2012). For the present literature review, a thematic approach was appropriate given the review question. As the aim was to explore current literature on perceptions of identity, a more narrative, or thematic approach was considered to be more appropriate than a traditional systematic review, in order to facilitate an exploration of findings. The concept of identity in care homes is under-researched, and a thematic overview of the literature enables the identification of new research questions and research directions, in addition to highlighting any limitations of previous research (Hodgkinson and Ford, 2014). A thematic approach has been used to address other literature review questions relating to views or perceptions (Thomas and Harden, 2008).

Typically, systematic reviews utilise a primarily quantitative approach (Dixon-Woods *et al.*, 2006) to comprehensively search for and identify all relevant studies, which are statistically analysed. Narrative reviews have been criticised for being too descriptive, unsystematic, and not transparent (Dixon-Woods *et al.*, 2004; Dixon-Woods *et al.*, 2006). A comprehensive search strategy is important to prevent bias (Centre for Reviews and Dissemination, 2006). However, a comprehensive search strategy is not limited to traditional systematic reviews, and has been incorporated in narrative and thematic style approaches (Popay *et al.*, 2006; Thomas and Harden, 2008; Snilstveit *et al.*, 2012).

The approach adopted for the present review was based on the process of 'thematic synthesis' outlined by Thomas and Harden (2008), which shares commonalities with 'metaethnographies' presented by Noblit and Hare (1988). Briefly, the methods are similar to those of a thematic analysis, used for primary research (Thomas and Harden, 2008;Snilstveit *et al.*, 2012). Themes are generated from the findings of included papers, and translated across the studies to provide a thematic overview of the current literature. Findings of included studies are categorised in to groups, or themes, and any divergent findings discussed. A thematic analysis of the current literature allows for the identification of salient themes, but remains flexible (Dixon-Woods *et al.*, 2005). This is a purely deductive approach, and is reliant on the initial conceptual framework under which the review was conducted, and on the content and quality of the included studies (Thomas and Harden, 2008; Snilstveit *et al.*, 2012). There is also some debate as to whether this type of review decontextualises the presented data, but while such criticisms may be valid, they do not detract from the overall usefulness of a systematically conducted, thematically presented overview of the current literature to inform research.

Table 1 presents the inclusion criteria for the present review. The exclusion criteria were

essentially the opposite of the inclusion criteria. The review includes residential homes and nursing homes. The distinctions between these two types of facility were discussed in Box 1, but for the sake of brevity, I shall refer to them together as "care homes" throughout the review. Papers based in other types of long-term care for the elderly (e.g. sheltered housing) were excluded, as the differing types of care may impact the findings of the review.

Table 1. Inclusion criteria

1.	Study based in a care home/residential home/nursing home
2.	English-language articles
3.	Study includes the perspectives of older people (aged 65 or over) residing in care homes
4.	Includes data on the concept of identity/self/self-concept within the care home
5.	Primary research study
6.	Non-intervention based studies

There were no restrictions on the country context of the studies, but only studies in English were included because the reviewer did not have access to translation facilities and did not read any other language. Also, the nuances of identified themes may be lost in translation. There were also no date restrictions imposed on the searches, as older studies could still highlight relevant themes for this topic.

Studies eligible for inclusion were those that investigated residents' perceptions of their identity following the transition to a care home. This did not have to be the overall aim of the study, but there had to be some data on identity for the study to be included in the review. Studies were not included or excluded on the basis of the particular definition of 'self' or 'identity' used. As there are multiple definitions or conceptualisations of 'identity' and 'self', the likelihood of finding papers that expressly used these terms with reference to the same definitions was minimal. Therefore, studies were included that focussed on self or identity regardless of the specific definition of theoretical background used.

Only studies that incorporated residents' experiences were included in the review. Studies that did not involve residents' perspectives were excluded, but studies that included residents

in addition to other participants, were included. Any data from non-residents discussed in this review will be clearly stated as such. Though family members or care home staff could contribute to the discussion on resident's identities, it is important to include residents' subjective perspectives and insights in to the issues surrounding their own identities. Older people with dementia may still be able to provide consent to participate in studies, and they should be included in research in order to inform services relevant to themselves (Dewing, 2002). Though interpersonal, identity management is also subjective and on-going, and residents may provide unique perspectives and insights to this process.

Intervention-based studies were excluded. The review uncovered a number of interventions that demonstrated an effect on residents' sense of identity within the care home. Such studies did not explore the impact of *care home* environment on identity, but rather the impact of a particular intervention on identity within the care home. These studies typically did not provide any pre-intervention data on residents' identities, and were therefore not eligible for inclusion.

Eligibility was not based on the methodology of the studies, i.e. whether quantitative or qualitative, as different methodologies could unearth equally relevant information relating to the aims of the review. This also ensured that the review showed widest possible breadth of the literature. Only non-intervention based studies that included primary data were included in the review; secondary analyses of data were excluded, as this would either involve providing an author's tertiary interpretations of others' analyses of primary data, or a re-interpretation of the dataset with a different objective for which the data were not originally obtained. As the data may have been initially collected for another purpose, the data may not accurately convey residents' perspectives on the issue.

#### 2.3.1. Search strategy

A systematic search strategy was used with the aim to find as many relevant papers as possible. Citing Doyle (2003), Thomas and Harden (2008) suggests aiming for 'conceptual saturation', which is similar to the notion of data saturation used in the analysis of primary data, whereby no new information is sought once similar concepts or themes emerge from the established pool of data. Not relying on statistical analyses of included studies means that such a strategy may be appropriate for a thematic review. However, the aim of reaching conceptual saturation was not adopted for the present review. Multiple studies may have

presented similar themes and concepts, any contextual and methodological differences between studies would provoke pertinent discussion. Any contextual or methodological differences between conceptually similar studies may have provided useful interpretations of findings, as well as helping to inform the methodology and design of the present study.

A list of search terms was created in collaboration with the supervisory team and with reference to other reviews on similar topics. Terms were grouped in two categories: 'Care homes' and 'Identity' (see Table 2). The categories of search terms were comprised of groups of free text terms divided by the OR Boolean operator, which were then searched together using the AND Boolean operator. Initial searches were conducted in June 2014, and updated in October 2015.

A PRISMA diagram of the search strategy is illustrated in Figure 2. The databases CINAHL, PsychInfo, ASSIA, and Medline were searched. Reference lists of included articles were searched for additional relevant references. Systematic reviews that were uncovered in the search process were used to identify further potentially relevant studies, but the reviews themselves were not included in the present review. Furthermore, the journals 'Ageing and Society', and 'Age and Ageing' were searched from their inception until the present. These particular journals were likely to publish studies that adhered to the review question, given their focus on understanding ageing, the "circumstances of older people in their social and cultural contexts", and psychological issues within gerontology.

Searches were further refined by the age of participants, where possible, on each database. Ages were restricted to those involving participants aged 65 and over, as this is the generally accepted definition of 'old age' in Western cultures, including the UK (World Health Organisation, 2015). The search strategy did not include adjectival terms that indicated age (e.g. "old", "aged"), as preliminary searches that included such terms reduced the number of search results to such a degree that it suggested that relevant studies were not indexed to illustrate participant age, and were thus being omitted.

The 'Care home' search terms were searched in the subject headings of papers, whereas the identity search terms were searched for in the abstracts. Preliminary searches suggested that many of the papers were not indexed to include 'Identity'-based search terms in the subject headings, particularly if issues relating to identity were not the main aim(s) of a paper.

Therefore, abstracts were searched for relevant identity-based terms to yield relevant papers that had not initially aimed to uncover data on these concepts, but presented findings including relevant information for the review.

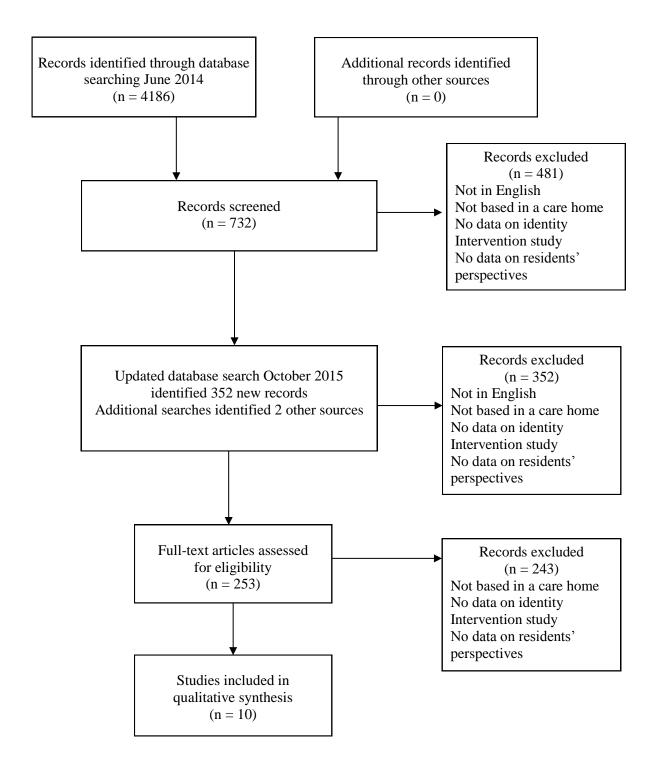
#### Table 2. Search terms

Primary	Search fields	Limiters
<b>Care homes:</b> Nursing home OR nursing homes OR care home OR care homes OR long term care OR assisted living facility OR assisted living facilities OR residential aged care facility OR residential aged care facilities OR senior living facility OR senior living facilities OR senior housing OR extra care housing OR homes for the aged OR intermediate care facilities OR skilled nursing facilities OR housing for the elderly OR residential facilities OR residential facility	Subject heading	Language: English
AND		
<b>Identity:</b> Identity OR self OR self-concept OR personhood OR ego OR biography OR social identity OR personal identity OR self* OR selfhood	Abstract	

#### 2.3.2. Data management and quality appraisal

One reviewer (KP) judged the titles and abstracts against the inclusion and exclusion criteria. Full text copies were then sourced for further analysis. Additional reviewers (CBW and CW) then independently checked the included papers against the criteria in order to rule out reviewer bias. Any disagreements were resolved via discussion.

# Figure 2. PRISMA diagram detailing the process of searching and identifying relevant papers



A standardised data extraction sheet was developed based on published guidelines in order to tabulate the data. Pertinent data relating to identity from each paper were extracted using the data extraction form (Appendix 2). The data extraction sheet was designed to gather information relevant for the review question. For each included paper, information was extracted on study characteristics, including which country the study was conducted in, research questions addressed within the paper, study design, sample size, data collection methods, and type of analysis conducted. Data were also collected on the definition of identity outlined in the paper, the overall findings of the study, and the themes that these findings fall under. Tabulating the data helped to make comparisons between studies and to identify relevant themes (Popay *et al.*, 2006).

Very few studies included in the present review incorporated data and verbatim quotes. This is often due to publishing requirements of journals and reporting styles (Sandelowski and Barroso, 2002). It was therefore difficult to achieve the level of thematic synthesis outlined in Thomas and Harden (2008). Nonetheless, broad themes were obtained by identifying recurrent or important concepts in the studies (Snilstveit *et al.*, 2012). While the aims and methods of most studies differed, common themes emerged and were used to structure the narrative discussion.

The decision to exclude on the basis of quality is often debated within qualitative research (Dixon-Woods *et al.*, 2006;Thomas and Harden, 2008). Quality appraisal is typically expected in systematic reviews (Toye *et al.*, 2014). However, excluding studies on the basis of quality could remove potentially relevant studies and does not necessarily distort the findings of the review or synthesis (Campbell *et al.*, 2011). Other reviews and meta-ethnographies have presented a quality appraisal and not excluded on the basis of quality (e.g. Toye *et al.*, 2014), which was the approach used for the present review.

Data were appraised for quality using the Critical Appraisal Skills Programme (CASP) (Solutions for Public Health, 2013) checklist, by KP. Papers were not excluded on the basis of quality. The purpose of the appraisal was to identify the quality of the evidence relating to identity in care homes in order to contextualise the conclusions that can be drawn from the current literature. The results of the CASP

quality checklist is presented in Appendix 1.

By totalling up the positive responses to the CASP questions, it emerged that half of studies were of medium-to-low quality (five 'yeses' or fewer), and half were of higher quality, receiving over five yeses for each question. While a qualitative approach was appropriate for each research question and study aims, some authors either did not explicate the justification for their methods or were unclear (Golander, 1995; Riedl et al., 2013; Anbäcken et al., 2015). All studies appeared to collect data in a way that addressed the research issue, utilizing in-depth or semi-structured interviews and observations. Most studies failed to consider the relationship between the research and participants (Golander, 1995; Cohen-Mansfield et al., 2000; Tester et al., 2004; Surr, 2006; Welsh et al., 2012; Riedl et al., 2013; Oosterveld-Vlug et al., 2014; Anbäcken et al., 2015), and most did not explicate the ethical considerations and process of consent in sufficient detail (Golander, 1995; Cohen-Mansfield et al., 2000; Tester et al., 2004; Surr, 2006; Moss and Moss, 2007; Oosterveld-Vlug et al., 2014; Anbäcken et al., 2015). However, while there was some inconsistency with the description of the analysis process and description of a rigorous approach, all studies presented a clear statement of findings.

In the following section, the methods and theoretical perspectives of the studies are discussed, and then the findings of the studies are presented thematically.

#### 2.4. Findings

#### 2.4.1. Methods used and inclusion/exclusion criteria

Ten studies were included in this review. An overview of these studies is presented in Appendix 2. Two studies were conducted within the United Kingdom. Surr (2006) in England and Wales, and Tester *et al.* (2004) in Scotland. All other studies were conducted in other countries: One study was conducted in the USA (Moss and Moss, 2007), one in Canada (Welsh *et al.*, 2012), two in Israel (Golander, 1995; Cohen-Mansfield *et al.*, 2000), one in the Netherlands (Oosterveld-Vlug *et al.*, 2014), one in Norway (Heggestad and Slettebø, 2015), one in Austria (Riedl *et al.*, 2013), and one in Japan (Anbäcken *et al.*, 2015). Nine of the ten included papers used solely qualitative methods, and one paper (Cohen-Mansfield *et al.*, 2000) combined quantitative and qualitative methods, though did not expressly state that it was a mixed methods study. All used interviews, whether structured or semi-structured, and four studies used observations (Golander, 1995; Tester *et al.*, 2004; Anbäcken *et al.*, 2015; Heggestad and Slettebø, 2015). Only three studies combined interviews with observations (Tester *et al.*, 2004; Anbäcken *et al.*, 2015; Heggestad and Slettebø, 2015). Heggestard and Slettebø (2015) stated that they conducted participant observations with fifteen residents with dementia, but only provided data on three residents' life stories.

The forms of data collection are presented in the data extraction table in Appendix 2. Eight studies were conducted over a period of time (Golander, 1995; Tester et al., 2004; Surr, 2006; Moss and Moss, 2007; Riedl et al., 2013; Oosterveld-Vlug et al., 2014; Anbäcken et al., 2015; Heggestad and Slettebø, 2015) ranging from 24 hours in total (Tester et al., 2004) to 24 months (Surr, 2006). These eight included interview-only studies and studies that included observations. Other studies were either unclear or did not state the length of the data collection period. Tester et al. (2004) completed observations at two-hourly intervals on different days of the week, covering over 24 hours. Though this is approximately four weeks of data collection in total, the length of each interval seems too short to obtain a breadth of different observations on each day. In addition, authors of other observation-based studies were unclear how long they spent in each care home at a time (Golander, 1995; Tester et al.; Moss and Moss, 2007; Riedl et al., 2013; Oosterveld-Vlug et al., 2014; Anbäcken et al., 2015; Heggestad and Slettebø, 2015). This suggests a difference in how authors conceptualise the transition process and identity management; studies conducted over a shorter period can be interpreted as perceiving any issues around relocating to long-term care or institutionalised identity management as being an event, rather than a process. This can impact on the depth and validity of the data obtained from these studies. It was also unclear whether authors obtained in-depth interview or observation-based data on multiple participants, or relied on a "snapshot" of particular residents' experiences.

The study by Cohen-Mansfield *et al.* (2000) was the only study to include multiple perspectives; those of the resident, their family members, and care home staff. All

other studies solely focussed on residents. Sample sizes varied across the studies; from an overall sample size of 78 individuals across two care homes (including 26 residents) to a sample size of six female residents. As most of the studies used qualitative methods, including observations, a smaller sample size enables the collection of more in-depth data (Cleary *et al.*, 2014), which is beneficial for the phenomenon under study. Thus the sample size of a study is not necessarily an indicator of quality.

Most studies collected data from multiple sites. Only Golander (1995) collected data in a single facility. A single-site study can provide in-depth data for a particular facility, whereas multi-site studies facilitates the comparison of findings across sites. However, none of the studies included in this review overtly compared and contrasted findings between sites.

The studies varied on whether they focussed on residents with a diagnosis of dementia, or care home residents in general. Four studies only included residents with a diagnosis of dementia (Cohen-Mansfield *et al.*, 2000; Surr, 2006; Anbäcken *et al.*, 2015; Heggestad and Slettebø, 2015), two had a mixed sample of residents with and without dementia (Golander, 1995; Tester *et al.*, 2004), and for Moss and Moss (2007) this was unclear. Three studies excluded residents with cognitive impairments (Welsh *et al.*, 2012; Riedl *et al.*, 2013; Oosterveld-Vlug *et al.*, 2014). Including studies that either included or excluded residents with dementia within this review may have uncovered different themes, as it was possible that residents with dementia may have different experiences to those without a diagnosis of dementia. Nonetheless, both residents with and without dementia offer equally valid and relevant perspectives on the impact of their identities within the care home environment, and should be included in this review.

Additional eligibility criteria varied between studies, including age-related criteria, length of residency in the care home, language, and physical infirmity. The minimum age restrictions for participants ranged from over 55 years of age to over 70 years of age. It is often necessary to state age restrictions for participants when applying for clearance from an ethics committee. However, Riedl *et al.* (2013) excluded residents without "mental stability" and those without the "cognitive ability

to answer questions", and those who were "bed-ridden". While this could be justifiable from an ethical perspective, excluding "bed-ridden" residents, who may be mentally stable, excludes the equally valid and relevant perspectives of a subsection of nursing home residents. The aims of the study were to explore how residents maintain their identity during their first year of residency in a nursing home, and "bed-ridden" residents may have offered an alternative perspective than those who were more physically able.

Only Moss and Moss (2007) determined eligibility on the basis of gender, including only male residents. Most other studies had sample sizes consisting mostly, or solely, of female residents; two did not provide information on the gender of participants (Tester *et al.*, 2004; Heggestad and Slettebø, 2015). This is most likely because of the gender gap within care homes, with women representing a larger proportion of the care home population (Office for National Statistics, 2014). This may have affected the type of themes that emerged in the review.

## 2.4.2. Theoretical perspectives/Definitions of identity

Each of the ten included studies either used a different definition of identity to one another, or did not provide a definition for identity (see Appendix 2). Tester *et al.* (2004), Anbäcken *et al.* (2015), and Welsh *et al.* (2012) did not provide a definition of self or identity. Moss and Moss (2007) used the framework of hegemonic masculinity, i.e. a definition of identity specifically focussed on male identities. Other definitions of identity focused on residents' roles (Cohen-Mansfield *et al.*, 2000), dignity (Oosterveld-Vlug *et al.*, 2014; Heggestad and Slettebø, 2015), conception of the body (Golander, 1995), socio-biography (Surr, 2006), and selfidentification within a relevant environment (Riedl *et al.*, 2013). Surr (2006) and Reidl *et al.* (2013) used more general definitions of identity that enabled participants to discuss multiple aspects. Despite the variety of definitions used, most studies based interviews on biographical knowledge or life-story work in order to uncover residents' narratives regarding their identities. It is not the aim of this review to explore these definitions in detail, but to merely highlight the variety of perspectives used within the current literature.

Only three studies in the review had the express aim to explore the concept of

identity in a care home (Surr, 2006; Riedl *et al.*, 2013; Anbäcken *et al.*, 2015). All other studies discussed identity as a sub-theme, and consequently provided comparatively little data on identity.

#### 2.5. Themes

Five themes were identified across the papers. These were: i) physical ability and dignity; ii) restrictions of the care home; iii) activities and hobbies; iv) work and social roles; and v) relationships inside and out of the care home. There were also three miscellaneous themes that warranted discussion due to their relevance to the review question, but appeared in a minority of studies; these were: personal possessions, appearance, and imaginary identities. Though not every paper demonstrated each theme, thematic categories were based on the frequency and prevalence of each theme across the studies.

## 2.5.1. Physical ability and dignity

All the studies mentioned the impact of decreased physical ability on residents' sense of self and dignity. According to Oosterveld-Vlug et al. (2014), the act of moving to a nursing home itself did not influence residents' sense of self. Rather, illness-related conditions affected their personal dignity. Advancing illness threatened residents' sense of self owing to their increased dependency on others to perform daily care (Golander, 1995; Oosterveld-Vlug et al., 2014). In particular, issues surrounding residents' physical health and experiences of frailty impacted their sense of self (Golander, 1995), feelings of "dignity" (Oosterveld-Vlug et al., 2014) and quality of life (Tester et al., 2004). Golander (1995) referred to residents' feelings of "betrayal" of their body as they experienced chronic illness and adapted to their ageing bodies, which meant they were less able to conduct daily activities. Physical infirmity meant that residents were less able to perform their usual activities, and activities that were salient for their sense of self (Moss and Moss, 2007; Welsh et al., 2012; Riedl et al., 2013; Anbäcken et al., 2015; Heggestad and Slettebø, 2015). Conversely, in Riedl et al. (2013), some residents downplayed their physical disabilities when nurses offered them help, and believed they could still perform activities themselves, apart from cooking and cleaning. Remaining independent was important to them, and the facility appeared to enable residents to act upon their independence where possible (Riedl et al., 2013).

### 2.5.2. Restrictions of the care home

Long-term care was also seen as a hindrance to an individual's independence and autonomy. The rigidity of the routines forced homogeneity across the residents (Golander, 1995) and made it difficult for residents to exert their individuality and independence (Golander, 1995; Oosterveld-Vlug *et al.*, 2014). Being able to make their own decisions was considered to be important to promote a sense of dignity (Oosterveld-Vlug *et al.*, 2014), but residents felt as though they were made to 'fit in' with the routines of the care home (Tester *et al.*, 2004). According to Oosterveld-Vlug *et al.* (2014), residents felt that they did not want to disturb nursing home staff for assistance, as they did not wish to be a burden.

Staff were identified as being key to promoting independence within the nursing home (Cohen-Mansfield *et al.*, 2000; Tester *et al.*, 2004). Findings in the study by Anbäcken *et al.* (2015) show that members of staff performed "scaffolding" to support residents to perform daily activities and promoting independence, by suggesting that they perform chores in the care home. Though in Anbäcken *et al.* (2015) study, this was only demonstrated with one resident, and no other studies provided examples of *how* participating members of staff supported residents in a similar way.

#### 2.5.3. Activities and hobbies

Six studies identified that it was important to residents to engage in activities and hobbies that were aligned with their previous activities and roles, and residents expressed sadness at being unable to perform these activities (Cohen-Mansfield *et al.*, 2000; Tester *et al.*, 2004; Moss and Moss, 2007; Welsh *et al.*, 2012; Riedl *et al.*, 2013; Heggestad and Slettebø, 2015). Residents tried to maintain their old "habits" as much as possible (Riedl *et al.*, 2013), but often could not engage in activities that were meaningful to them (Golander, 1995; Cohen-Mansfield *et al.*, 2000; Tester *et al.*, 2003; Heggestad and Slettebø, 2015). This was due to both the increased impairments associated with the ageing process, and the restrictions of the care home. Some of the activities that residents and family members listed as important to the resident were not available in the institution, and there was little choice of activities overall (Golander, 1995; Cohen-Mansfield *et al.*, 2000;

Oosterveld-Vlug *et al.*, 2014). In the study by Cohen-Mansfield *et al.* (2000), staff identified that TV watching was the most common leisure activity when in the care home, but residents stated that reading was their most common leisure activity from the past, suggesting that the residents were not engaging in activities they had previously enjoyed. It was unclear from this study whether residents did not engage in these activities because of failing eyesight or lack of resources. Golander (1995) also noted that the care home did not offer residents opportunities to learn new skills, and had limited resources for them to engage in new activities in order to stimulate new identity-relevant hobbies.

Residents also had little opportunity to go outside (Tester *et al.*, 2004; Anbäcken *et al.*, 2015), which reduced the number of activities they could engage in. Only Riedl *et al.* (2013) mentioned that residents were free to leave the facility to engage in particular activities. Residents may feel bored sitting in a care facility without any meaningful activities (Tester *et al.*, 2004). If a resident is unable to communicate what their meaningful activities or hobbies are, then staff and family members should work together to support the organisation of these activities. However, as Cohen-Mansfield *et al.* (2000) highlights, residents and their family members did not always agree on which activities were the most common, or meaningful, from their past. So care must be taken before making assumptions about what is considered to be meaningful to the resident.

Conversely, not all residents valued the opportunity to engage in activities, and some found that the routines of the care home were enough to keep them occupied on a daily basis (Tester *et al.*, 2004). However Tester *et al.* (2004) did not explore the reasons for this opinion. If a care home does not cater for a variety of interests, then residents may feel disinclined to take part.

### 2.5.4. Work and social roles

Six studies highlighted that residents' various social roles, particularly their work, was central to their sense of self (Cohen-Mansfield *et al.*, 2000; Surr, 2006; Moss and Moss, 2007; Riedl *et al.*, 2013; Anbäcken *et al.*, 2015; Heggestad and Slettebø, 2015). These roles changed due to the ageing process and transition to a care home, which in turn affected their identities. Former occupational roles remained important

for residents, but moving to long-term care made them feel useless (Moss and Moss, 2007; Riedl *et al.*, 2013; Anbäcken *et al.*, 2015; Heggestad and Slettebø, 2015). These roles ranged from paid occupations to the importance of being a homemaker and raising children. This was particularly central to a sense of self in Moss and Moss (2007). Participants cited their work roles when discussing their life stories, and their sadness when they could no longer work and feel useful (Surr, 2006; Moss and Moss, 2007). Residents attempted to maintain links with these roles by engaging in similar roles within the care home to feel useful. The emphasis on the importance of work in Moss and Moss (2007) in particular may be due to the solely male population within the study, whereas all other studies included in the review included men and women, though most had predominantly female samples.

## 2.5.5. Relationships inside and out of the care home

According to Cohen-Mansfield *et al.* (2000), the multiple identities of residents with dementia deteriorated significantly, and residents expressed great sadness over the loss of their many roles. Residents in other studies lamented over their diminished social roles, particularly in relation to their roles within their family (Surr, 2006; Moss and Moss, 2007). The family role was considered to be the most important role, and retained the most prominence following a dementia diagnosis (Cohen-Mansfield *et al.*, 2000). Similarly, Moss and Moss (2007) identified that male residents considered their roles as a spouse to be central to their identity, but moving to long-term care made them feel useless and no longer able to protect their spouses.

All studies highlighted that interpersonal relationships were important for residents. Relationships not only served to define their sense of self in the past and present, but also impacted their experiences of long-term care (Golander, 1995; Cohen-Mansfield *et al.*, 2000; Surr, 2006; Moss and Moss, 2007). Most participants across the studies mentioned losing contact with important individuals, particularly family members, either due to death or the transition to long-term care. Shrunken social networks impacted residents' "relational self" (Oosterveld-Vlug *et al.*, 2014), but regular visits from family can help to elicit a sense of identity (Cohen-Mansfield *et al.*, 2000). Residents often cited feelings of isolation and loneliness from the loss of familiar company (Tester *et al.*, 2004; Moss and Moss, 2007; Oosterveld-Vlug *et al.*, 2014; Anbäcken *et al.*, 2015).

The studies suggested that residents were not motivated to form relationships with other residents. Participants across the studies tended to blame other residents for the lack of interpersonal relationships in the care homes, as they considered other residents to be too severely cognitively impaired to warrant forming a relationship with (Golander, 1995; Tester et al., 2004; Moss and Moss, 2007; Riedl et al., 2013; Oosterveld-Vlug et al., 2014). Six studies identified negativity between residents with dementia and those without (Golander, 1995; Tester et al., 2004; Moss and Moss, 2007; Riedl et al., 2013; Oosterveld-Vlug et al., 2014; Anbäcken et al., 2015). Residents without dementia often spoke very negatively about residents with dementia, describing them as a "nuisance" (Golander, 1995), and made an effort to physically and socially avoid them (Golander, 1995). In Anbäcken et al. (2015), Tester et al. (2004), and Surr (2006) residents appeared to make more of an effort to establish friendships with one another and emphasised the positive feelings of inclusion following the formation of friendships with other residents (Surr, 2006), but in Tester et al. (2004) this was impeded due to impairments of speech and hearing. Additionally, it was not clear in Anbäcken et al. (2015) and Surr (2006) whether residents' positive interpersonal relationships with other residents included residents with dementia. Furthermore, the included studies did not explore this issue beyond residents' suggestions that those with dementia were too impaired to connect with. Only Golander (1995) briefly discussed the notion that distancing from residents with dementia was perhaps a defence mechanism to avoid the stigma of having dementia.

Participants tended to value relationships with members of staff more than those with other residents, largely due to the aforementioned issues around making connections with other residents (Tester *et al.*, 2004;Surr, 2006;Riedl *et al.*, 2013). However, these relationships and their impact on residents' identities were not explored in detail in the included studies.

## 2.5.6. Miscellaneous themes

Additional themes emerged in a small number of studies. Given their pertinence to the review question, they are discussed below.

## 2.5.6.1. Personal possessions

Two studies highlighted the significance of bringing physical items in to the care homes for some residents to feel 'at home' and reflect their sense of self (Tester *et al.*, 2004; Riedl *et al.*, 2013). These included clothing, photographs, and crockery, and residents stated that their possessions strengthened their identities (Riedl *et al.*, 2013), and helped them to feel 'at home' (Tester *et al.*, 2004). Possessions enable the resident to maintain memories about important social relationships and activities they can no longer perform (Riedl *et al.*, 2013).

## 2.5.6.2. Appearance

Two studies cited the importance of appearance to residents in maintaining a sense of self in long-term care. According to Tester *et al.* (2004), residents who were able to express their sense of self through their appearance felt more 'at home' in residential care, but did not expand on this point. Oosterveld-Vlug *et al.* (2014), found that residents, men in particular, became disinterested in their bodies and accepted the negative effects of ageing in this regard. Some women were more attentive of their appearance, and made an effort to wash their hair often and buy new clothes. However, they needed support from staff to achieve this, but the authors did not address how this was negotiated (Oosterveld-Vlug *et al.*, 2014).

## 2.5.6.3. Imaginary identities

Despite six studies including residents with dementia, only Cohen-Mansfield *et al.* (2000) explored the concept of imaginary identities. Older people constructed identities based on false memories surrounding achievements and elements of their biographies that were not true.

#### 2.6. Discussion

This thematic review provides an overview of the published literature that explores the impact of the transition to a care home on residents' identity. The search uncovered only ten studies that met the inclusion criteria, which demonstrates paucity of data surrounding this issue, particularly from residents' perspectives. Many of the studies were relatively recent (the oldest from 1995, but all other studies in the 21st century), suggesting that this is still a current and significant issue. The studies varied in quality, particularly around their justification for the research design, the relationship between the researcher and participants, consideration of ethical issues, and explication of the rigorousness of the data analysis process. Though the themes provide an insight in to the impact of the transition to a care home on residents' sense of identity, more research is needed that includes residents' perspectives, observational methods, and a more general overview of the concept of identity, rather than focussing on a particular aspect of identity.

Studies found that residents' physical abilities impacted their sense of dignity and identity, but particularly within the care home, as they were largely dependent on nursing staff. Past occupations and social roles formed a major element of residents' identities, with occupational roles and family roles being the most dominant aspects. Residents attempted to incorporate elements of their occupational roles in to the daily life of the care home, such as completing chores or helping other residents. However, the restrictions of the care home limited residents' ability to exert their independence and individuality, though only the study by Anbäcken et al. (2015) evidence that staff actively supported residents provided to achieve this. Furthermore, diminished social networks and changed familial roles severely impacted residents' sense of self. They had limited opportunities to create new identity-affirming relationships, because their peers were perceived as being too severely impaired to bond with, and residents with dementia were actively avoided. From a practice perspective, care home staff could do more to promote interpersonal relationships within the facilities, and to address some residents' negative perceptions of their peers.

While some studies highlighted how keeping meaningful possessions or activities, and regular contact with family members, can maintain residents' identities, there is little evidence exploring the interpersonal strategies that residents used to maintain their identity in the care homes. Only Golander (1995) mentioned the potential usefulness of residents without dementia distancing themselves from residents with dementia, to avoid stigmatisation, but did not discuss this possibility in depth. Future research should not only address the aforementioned themes in more depth, but also explore other mechanisms used by care home residents to maintain a positive sense of self, to determine whether the institution can support residents' identities.

All the studies included in the review used qualitative methods, with only one combining qualitative and quantitative methods (Cohen-Mansfield et al., 2000). A qualitative methodology and associated methods facilitates the inclusion of more nuanced, subjective experiences in a study. Furthermore, the process of identity construction occurs, and can change, over a period of time (Reicher et al., 2010). Identity is therefore likely to be influenced by changing interactions and relationships, and residents' perspectives of their experiences of the transition to a care home, and their subsequent adjustment may also change over time. Given the interpersonal and context-dependent nature of identity construction (Tajfel and Turner, 1979; Reicher et al., 2010), observational methods can enable more in-depth, contextualized data, and uncover themes that may not have arisen through interviews (Ritchie, 2003; Guest et al., 2013). However, only four studies used observation methods, and only three of these combined observations and interviews. This suggests that there not only has to be more research on this topic in general, but more research that utilizes relevant methods in order to produce in-depth, contextualized data.

Only two studies were conducted in the UK (Tester *et al.*, 2004; Surr, 2006). This was surprising given the substantial UK policy focus on dementia and ageing, and the importance of maintaining an older person's identity in order to promote personcentred care. This suggests that more research is required to further explore the concept of identity in care homes, particularly from the residents' perspectives. Furthermore, though the review only included studies based in similar institutions (i.e. residential homes or nursing homes), therefore the differing social and geographical contexts of these studies may produce different results due to potentially different policies, funding, ethos of care, and cultural perceptions of ageing.

This review demonstrates that the transition to a care home impacts a resident's identity in a variety of ways, predominantly their relationships with family members, and perceptions of their various former roles. Furthermore, as discussed throughout, this review did not uncover any UK-based studies that included residents' perspectives through interviews and observations, conducted longitudinally, and

exploring the impact of the transition to a care home on residents' overall sense of identity, and how they manage this on a daily basis.

### 2.7. Limitations and strengths of the review

These conclusions were drawn from a limited body of research of mixed quality. Though the review was conducted rigorously, the results should be interpreted with caution. The data extracted may not be a true reflection of the findings, due to poor reporting and reliance on authors' interpretations. It is important to conduct high quality research in to the concept of identity within care homes, in order to inform and improve care for older people. There are a limited number of studies that explore this in depth, with most exploring identity as a sub-theme.

The review only included studies that incorporated residents' perspectives. This approach omitted studies that excluded participants on the basis of cognitive impairment and ethical issues relating to consent, and thus relied on family members and/or staff as participants. Such studies can provide useful insights in to the concept of identity in care homes. However, the purpose of this review was to understand the current literature in relation to residents' own experiences, and the themes relating to how they felt the care home influenced their sense of self. Though family members and staff perspectives are equally valid, their interpretations of events may differ from those of the resident, as Cohen-Mansfield *et al.* (2000) highlighted. While incorporating multiple perspectives and interpretations may yield relevant data for future research, it was considered too broad an approach to take for this review.

This review benefits from a broad, comprehensive search strategy across multiple databases and journals. The use of broad search terms enables the identification of relevant papers that included data on identity but did not necessarily aim to explore identity in care homes. The search terms enable the inclusion of papers that offer a variety of definitions and conceptualisations of identity. Though there are important contextual or cultural differences to consider with international studies, this review has nonetheless identified relevant studies from an array of countries.

## 2.8. Implications for future research

This review has demonstrated the paucity of research in to the concept of identity in

care homes that focuses on the residents' own perspectives, and methodological limitations of these studies. Overall, more studies need to explore the how residents' identities are impacted following relocation to a care home. Future studies must clearly define the concept of identity used. It may be useful to explore identity from a more general perspective, rather than using a definition that focuses on particular aspects of identity, to explore identity as a whole. Furthermore, residents should be included in the research as much as possible to appreciate their own experiences and interpretations, as well as those of family members and staff, to potentially compare and contrast themes. Studies should utilise a broader array of qualitative methods to adequately explore this interpretational and context-dependent phenomenon. Finally, more UK-based studies are needed, particularly given the significance of identity-relevant, person-centred care highlighted in recent policy.

The results of the thematic review provide a foundation for the research conducted for this PhD. The next chapter will discuss the methods for the current study, and how they address the aforementioned gaps in the literature.

# **Chapter 3: Methodology**

#### **3.1. Introduction**

This chapter provides a discussion of the research philosophy that underpinned the methods used in the study. This includes a description of the qualitative approach and criticisms of it, the case study method, and the decision to incorporate a constructivist/symbolic interactionist approach alongside the Social Identity Perspective (SIP). The working methods are presented in Chapter Four. This includes the sampling strategy, data collection process, the process of data management and analysis, and the ethical issues of the study.

Chapter Two presented a review of the literature on the concept of identity in care homes. It illustrated a lack of studies investigating identity in care homes, particularly from the residents' perspective, with the concept of identity being poorly defined in many cases. The review also highlighted the predominantly qualitative approaches that have been used, utilising interviews and/or observation-based methods to explore subjective experiences. Limitations included the descriptive nature of most studies with shallow interpretations of findings (possibly due to word limits in journals), and little appreciation for the significance of context-based interactions. A qualitative approach that addresses these limitations could uncover a more in-depth understanding of the impact of the transition to a care home on residents' identities and the process of identity management within this particular context. This PhD research seeks to address this deficit by exploring the management of identity within care homes for older people through the following aims and objectives.

#### **3.2. Research question**

How does the context of the care home influence residents' sense of identity?

## 3.2.1. Aim

To understand how the context of the care home can influence residents' sense of identity.

## 3.2.2. Objectives

- To describe the processes used by care home residents to construct a new identity or maintain former identities within the care home context.
- To explore the role of care home staff, other residents, and significant others in the management of identity.
- To explore the role of the care home context on the management of identity.
- To understand the important elements of residents' individual identities prior to the transition to the care home, and how they changed post-transition.

The research paradigm and research design should be influenced by the research question(s) (Green and Thorogood, 2014). As the aims of the thesis emphasise the exploration and understanding of subjective experiences, a qualitative case study was the most appropriate method to achieve the research objectives. The following sections address how the decision to adopt the chosen methodology was made.

### 3.3. Research paradigms: a brief overview

Research methodology can be divided into two main approaches: quantitative and qualitative. These approaches are informed by different paradigms, or belief systems, that guide how we approach a research topic, and range from positivism to constructivism. These paradigms are characterised by their ontology, epistemology and methodology (Guba and Lincoln, 1989;Guba and Lincoln, 1994). **Ontology** refers to what constitutes reality: Is reality constructed from facts that can be scientifically verified (positivism) or is it fluid (constructivism) (Patton, 2002;O'gorman and Macintosh, 2015)? **Epistemology** refers to what we can constitute as being valid knowledge and how to obtain it: Can knowledge be understood objectively (positivism) or is it subjective (constructivism) (Maykut and Morehouse, 1994;O'gorman and Macintosh, 2015)? Lastly, **methodology** refers to how the theoretical framework is used to guide research, and is reflected in the chosen methods (Silverman, 2005;O'gorman and Macintosh, 2015).

Quantitative approaches are generally located across the positivist paradigm, which is underpinned by an objectivist or realist ontology, where reality is constructed from measurable facts that can be logically explained. Quantitative approaches can use experimental methodologies, and use methods such as surveys or trials to uncover knowledge (Guba and Lincoln, 1994;Green and Thorogood, 2014). A quantitative, or positivist, approach would be inappropriate for this study. The concept of identity management in care homes is under-researched, and a more qualitative, exploratory design would facilitate a more in-depth understanding of the research question through the inclusion of subjective experiences and context-based interactions. Furthermore, such a poorly understood concept is difficult to standardise and quantify. Adopting a quantitative approach risks assuming homogeneity of identities, which, by definition, are fluid, subjective, and context-dependent.

Qualitative approaches are generally located along the constructivist paradigm (O'gorman and Macintosh, 2015). There are multiple theoretical and epistemological approaches to qualitative research, though most generally share a rejection of a positivist methodology (Green and Thorogood, 2014). Constructivism is underpinned by a subjectivist ontology, suggesting that knowledge is subjective and open to different interpretations, more so than quantitative research. Constructivism endorses a hermeneutic/dialectical methodology (Guba and Lincoln, 1994). A hermeneutic methodology involves a dialectic, iterative, process between participants and the researcher. Social construction of knowledge, or meaning-making occurs through interaction "between and among investigator and respondents" (Guba and Lincoln, 1994: 111).

## **3.3.1.** Research paradigms: the current study

Ontologically, people who reside in a care home may have different interpretations of the transition process, their identities, and how the transition to long-term care influenced this, which is based on differing social realities and contexts. These interpretations may also change over time. For the current study, it was necessary to adopt an ontological position that acknowledged the multitude of possible perspectives on the issue of identity management in care homes, and that differing perspectives were equally valid. Constructivism and symbolic interactionism are two ontological positions that enable this, and will be discussed in more detail in Section 3.4.

Epistemologically, many of the theories surrounding identity management,

particularly the Social Identity Perspective, emphasises that self-concept is coconstructed through interaction with others (whether individuals or groups), and is subjective (Tajfel, 1982; Howarth, 2002). Therefore, taking a qualitative approach as this in the current study acknowledges the significance of the Other in identity management, and the subjectivity of experience.

Methodologically, as a lot of 'identity work' is unconscious and/or interlinked with everyday interactions, the study required a methodology that enabled the inclusion of multiple perspectives that occur through interaction, including interaction with the researcher. Therefore, a qualitative study with a constructivist and symbolic interactionist ontology, subjectivist epistemology and utilising a hermeneutical/dialectical methodology was deemed most appropriate.

#### **3.3.2.** Qualitative methodology

A qualitative methodology is ideal for studies that aim for an in-depth understanding of a phenomenon, and acknowledges multiple subjective interpretations. Older people, their significant others, and members of staff may each interpret how the transition to a care home impacts the resident's sense of identity. Through qualitative methods, participants can identify issues that are relevant to them (Denzin and Lincoln, 2000) and offer their own interpretations. Each perspective is equally valid, and may provide useful insights in to the process of identity management within a care home.

Typically, qualitative research is conducted with fewer participants in comparison to quantitative studies (Green and Thorogood, 2014). A greater number of participants enables the generalisation of results, which is typically an aim of quantitative research (Marshall, 1996;Polit and Beck, 2010;Green and Thorogood, 2014). Conversely, qualitative research does not necessarily seek widely generalisable results, but aims to provide rich, contextualised data to understand a phenomenon, that may be transferable to other contexts (Polit and Beck, 2010). This is best achieved through smaller sample sizes (Geertz, 1973;Cleary *et al.*, 2014).

Identity construction is an on-going social process, recognised through contextualised interactions and relationships; it cannot be adequately explored with

short-term, positivist methods. This is despite Tajfel and colleagues adopting positivist methods in their own experiments (Tajfel, 1968;Tajfel, 1978;Tajfel and Turner, 1979;Tajfel, 1982;Turner, 1982;Howarth, 2002).

As discussed in Chapter One, other people are essential in the co-construction of identity; therefore, other residents, care home staff, and significant others who visit care home residents are involved in daily interactions with the older person, and can influence identity management. A qualitative study will enable the exploration of identity management within care homes from the perspectives of care home residents, significant others, and members of staff, as well as exploring the relationship between these groups of individuals. This "thick description" of the phenomena (Geertz, 1973) will produce 'rich' data with which to better understand the concept of identity management following the transition to a care home.

Qualitative research can be subject to criticism. Some consider it 'unscientific' and anecdotal, particularly given the tendency towards smaller sample sizes that restrict the generalisability of findings (Murphy and Dingwall, 2003;Polit and Beck, 2010). Others have incorrectly assumed that there is a polarisation between qualitative research as inductive, and quantitative as deductive. Not only does this stance further the division between quantitative and qualitative research, but also assumes that qualitative research cannot be scientific (Murphy and Dingwall, 2003). To argue that qualitative research is unscientific is to support a realist approach, whereby neutral and rigorous research can achieve real critical distance, and thus reveal the 'truth'. As discussed in more detail in Chapter Four, there are strategies for maximising the quality of qualitative research, by improving its transferability, dependability, credibility and confirmability (Lincoln and Guba, 1985). By adopting these strategies in this PhD study, the data can be said to be of good quality, with a clear audit trail, and findings can be transferable to similar contexts.

### **3.4.** Theoretical perspectives of the thesis

There is a broad array of theoretical perspectives to take within a qualitative standpoint. However, any adopted perspective should be congruent with the objectives of the study (Green and Thorogood, 2014). Using the Social Identity Perspective from a symbolic interactionist or social constructivist perspective

enables this. As discussed in Chapter One, Social Identity Theory (SIT) (Tajfel, 1982;Wetherell, 1996) and Self-Categorisation Theory (SCT) (Turner and Oakes, 1986; Turner *et al.*, 1987; Hogg and Abrams, 1988; Oakes, *et al.*, 1994) were initially developed to explore group membership and intergroup behaviour. Jointly, these theories are known as the Social Identity Perspective (SIP) (Reicher *et al.*, 2010).

As discussed in Chapter One, SIP has been criticised for its overly positivist methods that focus on the individual level, and fail to incorporate social context and interactions (Turner and Oakes, 1986). This is despite suggestions that SIT and SCT assume an interaction between psychological and individual processes, rather than individualism (Turner and Oakes, 1986). However, SIP can be understood through the lens of symbolic interactionism and social constructivism to, essentially, 'fill the positivist gaps'. This does not detract from the relevance of the Social Identity Perspective. By combining the SIP with elements of symbolic interactionism and social constructionism, researchers can explore the identity process as well as the influence of interactions and social context. I briefly explain symbolic interactionism and their relation to SIP below.

#### **3.4.1.** Symbolic interactionism

Symbolic interactionism was created out of the Chicago School, which suggested that self and society are engaged in mutual creation of the other (Hermanowicz, 2013). This is useful for understanding how self determines and is determined by shared symbols through interactions with others. Symbolic interactionists argue that meanings and social knowledge are in constant interpretation (Blumer, 1969), and thus reject the objectivism within positivist approaches. The individual and the social context are inseparable, and in order to understand one, we must understand the other. People interact and make sense of the environment through context-dependent interactions using shared symbols, such as language, actions and social representations (Moscovici, 2000). Our interactions and behaviours evoke reactions from others, which in turn influence our subsequent behaviours. As such, interactions with others in different social environments or situations may alter individuals' behaviours (Laing and Esteron, 1964). Goffman (1959), James (1890), and other symbolic interactionists suggest that individuals display types of 'selves'

depending on the social setting in which the individual finds themselves. It is these everyday interactions that facilitate the orientation of the individual in the social world (Berger and Luckmann, 1966). This is obviously related to the aforementioned notion within the Social Identity Perspective, that individual's identities can shift depending on the salient context (Tajfel and Turner, 1979;Turner, 1982;Hogg and Abrams, 1988;Reicher *et al.*, 2010). The care home is a new social environment for older people, and interactions may thereby alter their behaviours and self-perceptions.

#### **3.4.2.** Social constructivism

Social constructionism and social constructivism are concerned with the experience and interpretation of reality, and the social nature of meaning-making. Like symbolic interactionism, social constructionism and social constructivism are removed from the objectivism within positivist approaches. Social constructionism and symbolic interactionism are also similar to one another in that both traditions consider people to construct meaning and identities through everyday interactions via shared symbols and understanding (Mead, 1934;Berger and Luckmann, 1966;Bjarnason, 2003).

Some authors emphasise the difference between constructionism and constructivism (Crotty, 1998). Social constructionism is concerned with the social construction of seemingly abstract concepts and principles (e.g. money), arguing that, "the content of our consciousness...is taught by our culture and society..." (Owen, 2007: 115). Knowledge is sustained by social processes, such as interaction and communication, which generate shared interpretations of reality (Burr, 1995). Social constructivism, on the other hand, takes a more individualistic approach and suggests that the observer creates reality through their experience and interpretation of it. There can be multiple possible realities that are as 'true' as each other, because reality cannot be objectively measured. As Crotty (1998) states:

"It would appear useful, then, to reserve the term <u>constructivism</u> for epistemological considerations focusing exclusively on 'the meaning-making activity of the individual mind' and to use *constructionism* where the focus includes 'the collective generation [and transmission] of meaning."". (Crotty, 1998: 58)

Nonetheless. these two approaches are very similar ontologically and epistemologically: constructionism and constructivism are both concerned with the social construction of reality, either at the individual level (constructivism) or cultural level (constructionism), and the rejection of an objectively measured reality. Consequently, authors such as Charmaz (2000; 2006) use the terms interchangeably or simply use 'constructivism' to refer to the general concept of a social constructed reality. For the purposes of this discussion and the overall thesis, it is irrelevant to focus on the differences between these two concepts. The main focus is on the underlying ontology and epistemology in relation to SIP and the overall aims of the research, i.e. truth is not absolute, but consists of multiple socially constructed realities within specific contexts; interaction between individuals can shape interpretation of objects and events. Thus, identities are socially constructed by virtue of a) the socially constructed meanings behind perceived 'group' differences (e.g. being a care home residents vs. not being a care home resident); b) the significance of social interaction for the interpretation of [group] differences and subsequent categorization.

The aim of this research is to explore how the transition to a care home influences resident's sense of identity and how resident manage their identity within the home, by exploring interactions and relations with relevant stakeholders. Each participant may hold a different perspective on/about his or her identity in the care home, which can be influenced by their own beliefs, the contexts, and other individuals with whom they interact. Each interpretation of events is equally as valid as other interpretations.

## 3.4.3. Study design

The choice of research design should be influenced by the research question (Silverman, 2011). Saunders and Thornhill (2009: 600) defined a research strategy as "the general plan of how the researcher will go about answering the research questions". Whereas Yin (2009) suggested that a research strategy should be selected on the basis of a) the extent of control an investigator has over behaviour, b) the degree of focus on contemporary or historical events and c) type of research question. There are multiple types of research strategies available, with many overlapping features (Saunders and Thornhill, 2009), including (quasi-) experimental

designs, surveys, grounded theory, participatory studies, ethnographies, and longitudinal studies, among many others.

A case study strategy was deemed to be an appropriate strategy for this PhD research, given the aforementioned aims and objectives, particularly the strategy as described by Yin (2009). Using a case study strategy will enable the iterative analysis of multiple perspectives within the context of the care home, and examine patterns in responses across multiple experiences. A more in-depth discussion of the research paradigm follows in the next sections, and a detailed description of the methods used will be discussed further in Chapter Four.

#### 3.5. Case study design: an overview

Case study has no firm definition (Walshe, 2011). There a multiple approaches to case studies, typically varying on whether they focus on the unit of the study, the product of the investigation or how the data are reported (Wolcott, 2002), or the process of inquiry (Anthony and Jack, 2009). There are also methodological differences. Two key approaches to the case study method are provided by Yin (2009) and Stake (1995). Their approaches share many similarities, but also important differences. Briefly, Yin does not overtly state his epistemological position, though his approach resembles a positivist stance, particularly with his focus on establishing conditions for maximising validity and reliability. Stake, on the other hand, emphasises an epistemological position more closely aligned with a qualitative methodology and constructivist epistemology (Stake, 1995; Yazan, 2015). For Stake (1995: 2), a case is a bounded system, which is investigated "as an object rather than a process", whereas Yin (2009) posits that a case cannot be separated from its context. Stake emphasises a flexible approach to develop an understanding of the phenomenon under study, whereas Yin's approach acknowledges the case study as a method, rather than the object of research itself. Both Yin and Stake support the use of multiple data sources.

Though an approach influenced by Stake could be relevant for the current study given its constructivist epistemology, Yin's approach also has its merits, despite its positivist leanings. A case study strategy influenced by Yin addresses "who", "what", "where", "how" and "why" questions, in addition to Yin's emphasis on the

contextual nature of a phenomenon, which lends itself to a naturalistic inquiry (Denzin and Lincoln, 2000) that is congruent with the aims and objectives of the current study. A case is a phenomenon under study that is examined within its context, where the boundaries of the phenomena and context are not clearly evident (Yin, 2009). Identity management is not a clearly bounded phenomenon and is likely to include personal and social issues preceding and following the physical relocation to the care home. Additionally, the researcher has no control over the events under study or behaviour of participants, which Yin (2009) posits is a necessary consideration when selecting study design.

In the current study, the researcher has no control over the identity management process, but can directly observe interactions and interview persons involved to achieve a holistic understanding of a phenomenon. A qualitative inquiry that incorporates the relativist ontology and subjectivist epistemology of symbolic interactionism with social constructivism fits well with Yin's (2009) case study approach, due to the emphasis by the latter of the significance of the relationship between the phenomena under study and its context. Furthermore, approaches suggested by Stake and Yin are not necessarily mutually exclusive. Incorporating flexibility and dialectic within a structured process can develop in-depth understandings of identity in care homes, whilst improving the credibility of the study. Thus Yin's (2009) approach to case study was considered to be appropriate for the current study.

Yin (1981) identifies three types of case study: exploratory, descriptive, and explanatory. Researchers may wish to go beyond the description of a phenomenon and examine the reasons and explanations behind it. The aims and objectives of this study support an exploratory design. Questions in semi-structured interviews and during observations will encompass issues preceding and following the transition to explore identity maintenance or change. Causal understandings of the phenomena may facilitate improvements to care.

Data used for a case study approach can be qualitative, quantitative, or a mixed methods design (Yin, 2009). Case studies can include multiple methods and a variety of sources, as a phenomenon under study may not be bounded to a particular source

(Yin, 2009). Case studies facilitate a longitudinal, triangulated design (Walshe, 2011). The triangulation of semi-structured interviews and participant observation in a longitudinal, multi-case design will produce in-depth information about the impact of transition on identity in long-term care.

Yin (1981) also identified two types of design: single-case design and the multiplecase design. A single case design involves just one case in the study, whereas a multiple-case design includes more than one case. A single case design is used when the case represents a typical or unique case. A multiple-case design is used when proposing an explanation between or across a number of cases. A multiple-case study can be considered to be more robust and have more analytic benefits than single-case designs (Yin, 2009). A multi-case design will strengthen the findings by helping to identify common themes across cases. Repetitions of responses within and across cases are likely to indicate a shared perception of the phenomenon under study. Using a multi-case design will enable the researchers to compare and contrast findings within and across different care homes to uncover alternative perspectives of the phenomenon.

The proposed design will firstly, reduce the possibility that a short-term event is interpreted as more important than it is to the participants over time; and secondly, explore the relocation process and identity from multiple perspectives in the context of their origin (Walshe *et al.*, 2008). This approach has been used by others where multiple and complex perspectives were apparent (Walshe *et al.*, 2008). The definition of the case will be explicated below.

## 3.5.1. Components of case study design

Yin (2009: 27) identifies the following five components of research design as especially important for case studies:

- 1. A study's questions;
- 2. Its propositions, if any;
- 3. Its unit(s) of analysis;
- 4. The logic linking of the data to the propositions;
- 5. The criteria for interpreting the findings.

Each of these components shall be addressed in the following sections.

## 3.5.1.1. Study questions

To reiterate, the current study poses the questions '*how* do older people experience the process of transition?' and '*how* does this impact their identity?' The questions were established from exploring the current research and policy context of care in care homes, narrowed further by the literature review. This reflects Yin's (2009) conditions for use of case studies, i.e. that the study questions should address "who", "what", "where", "how" and "why" questions. Therefore, the nature of the research questions met Yin's (2009) criteria for using case studies.

## 3.5.1.2. Theoretical propositions

Theoretical propositions help to guide the case study research (Yin, 2009). They can act as a tool for developing questions and concepts, and focus attention on what should be explored within a research study. Theoretical propositions are continuously revisited in the light of new data and amended, if necessary. This iterative approach enables the researcher to constantly compare the data with theory "iterating toward a theory which closely fits the data" (Eisenhardt, 1989: 541). Stake (1995) does not adopt this strategy, and instead recommends a more naturalistic approach. For the present study, theoretical propositions have been used to guide the research.

The Social Identity Perspective was used as an interpretative lens through which to understand the findings. Theoretical propositions guided the research, and were amended as data collection progressed. They were based on an understanding of the care home environment from the literature and personal experience, and on knowledge of the current identity literature and research surrounding life in care homes.

The theoretical propositions of the present study are:

• Personal and social identities are re-negotiated within the context of the care home in light of new social relationships and interactions.

- Maintaining links with previous social networks (e.g. relatives and friends) and habits (e.g. daily routines, personal décor) is important to maintain a sense of self.
- The care home environment has the potential to accommodate a multitude of identities with adequate support from individuals and appropriate resources.

The purpose of the present study was not to create a theory, but to explore the concept of identity within care homes. Nonetheless, the proposed theoretical propositions were used to guide data collection and analysis. They informed the development of the initial topic guide, along with the literature, and served as prompts during observations. Theoretical propositions remained flexible and were iteratively addressed throughout the research process (Yin, 2009), therefore enabling them to inform the analysis of the data.

# 3.5.1.3. Case and unit of analysis: definition

The case and unit of analysis of case study research design is particularly complex to define (Yin, 2009). To further this complexity, there is also much ambiguity surrounding the difference between a case and a unit of analysis (Grünbaum, 2007). Authors suggest that the case and unit of analysis are identical (Miles and Huberman, 1994; Patton, 2002), suggesting that "cases are units of analysis" (Patton, 2002: 447). Conversely, Berg (2001: 231) states that "The unit of analysis defines what the case study is focusing on (what the case is), such as an individual, a group, an organisation, a city, and so forth". Yin (2009) is also particularly vague and inconsistent regarding the difference between case and unit of analysis, and states that the two are identical: "A major step in designing and conducting a single case is defining the unit of analysis (or the case itself)." (Yin, 2009: 52). Yet when discussing multi-case design, Yin (2009) differentiates between case and unit of analysis with reference to 'embedded case studies' where the case is split into different units of analysis, as opposed to a holistic case study, which has one unit of analysis for each case, though this does not necessarily clarify a definition of either a case or unit of analysis. There are multitudes of justifiable ways of defining a case or unit of analysis; it can be an individual person, or some other event or entity, such as a process, or an institution, to name a few examples.

For the present study, the case was defined as the individual care home. According to Yin (2009), a case study strategy is appropriate when the boundary between the phenomena under study is indistinguishable from the context. While the concept of identity within the care home is the phenomena under study, it is difficult to extract this concept from the context of the care home itself. It is likely that participants' thoughts and feelings about living in a care home prior to the transition, the environment itself, and interactions that occur within the care home, will all influence the phenomena under study. This is particularly pertinent as the care home is likely to be residents' most salient source of interaction, and context-bound interactions are an important element of identity construction (Turner, 1982; Hogg and Abrams, 1988; Oakes, *et al.*, 1994; Reicher *et al.*, 2010). Defining the case as the individual care home allows for the interplay between residents' sense of identity, and how this is managed on a daily basis, within the context of the care home.

A multiple case study approach was conducted, and thus multiple care homes were involved. The individual care home was the most appropriate definition for the case given the significance of context for the formation of identity and identity management. The care home is the salient context for the residents, and is their primary place of residence and social interaction. By defining the case in terms of the care home, the focus is on the physical and social environment within the care home, such as the daily interactions between residents and staff members. Defining the case to incorporate multiple perspectives within the salient social environment will facilitate the exploration of the phenomena in its real-life context. Furthermore, this definition will facilitate the use of multiple perspectives to explore the phenomena of identity beyond the boundary of the physical relocation. Multiple cases would also allow for the assessment of similarities and variability in experiences and perceptions across different care homes, as different care home characteristics and practices may produce different results.

The unit of analysis should be related to the research questions (Yin, 2009). Given the objective to include multiple stakeholders' perspectives, such as residents, care home staff and significant others, an embedded design was considered to be appropriate. The participants can be grouped in to residents, their significant others, and members of staff, which could be considered to be an embedded unit of analysis, i.e. residents serve as one unit of analysis, and their significant others as another unit. As identity is socially constructed, incorporating multiple units of analysis (stakeholders) within the case (care home) can help to identify similarities and differences among the units of analysis. The sample and participants will be discussed further in Chapter Four.

Linking data to propositions and the criteria for interpreting the findings are both related to data analysis. The data should reflect the initial theoretical propositions, and will determine an appropriate type of data analysis (Yin, 2009). The researcher should be aware of the choices of analysis during the design phase of the study in order to "create a solid foundation for the later analysis" (Yin, 2009: 34). However, Yin's description of analytic techniques is limited. Briefly, there are five techniques for linking data to the theoretical propositions: pattern matching, explanation building, time-series analysis, logic models, and cross-case synthesis (Yin, 2009). Due to the subjectivity of the phenomenon and the inductive design of the study, it is likely that there are multiple possible explanations for the findings. A more in-depth discussion of the data analysis process will be presented in Chapter Four, and any alternative explanations for disconfirming findings will be addressed in the discussion of the thesis.

## 3.6. Summary

This chapter has addressed the ontological, epistemological and methodological approaches taken in this study. To reiterate, the theoretical and philosophical foundation of this study acknowledges the subjective nature of experiences and perceptions and that there is no objective 'truth' to measure systematically. The Social Identity Perspective has been seldom used in care home-based research and offers alternative source of theoretical propositions and an interpretive lens for the data, with the aim of addressing the aforementioned "how" and "why" questions of the study. From a constructivist approach, participants may differ in their perceptions of the transition to a care home and how it impacted their sense of self, given the inevitable differences in their identities owing to a variety of backgrounds and personal contexts. Furthermore, from a symbolic interactionist approach, the identity management process involves meaningful social interaction with others in differing

contexts, with the care home providing a new salient source of interaction. Therefore, it is important to adopt an approach that takes these interactions and contexts in to consideration. Adopting a case study strategy proposed by Yin (2009) facilitates the achievement of these aims and objectives in a transparent, systematic manner.

The next chapter will discuss the working methods of the study in light of these decisions.

## **Chapter 4: Working methods**

In the previous chapter I explained the theoretical perspectives and methodology adopted for the study. This chapter addresses the working methods of the study, including case selection, negotiating access, and sampling. The rationale behind the choice of data collection methods and analysis is discussed, including the process of data collection, and ethical issues. I will also explain how I constructed a hermeneutic circle between the data collection process, methods and analysis. The final section addresses the issues relating to quality in qualitative research, and in relation to this study.

#### **4.1. Sampling and recruitment of care homes**

As discussed in Chapter Three, the definition of the case was the individual care home. The present study used a multi-case design. Including multiple care homes enhanced the exploratory nature of the study by establishing whether different types of care homes promoted different experiences of identity management. Multiple cases could also provide alternative interpretations as to why the identity management process was affected in particular ways, or not in others. Multiple-case designs use either literal or theoretical replication (Yin, 2009). Literal replication entails selecting cases with similar settings that are expected to produce similar results. Theoretical replication is used when cases have different settings and are expected to achieve different results. It was assumed that differing variables across the care homes may contribute to differing experiences of care home life; for example, care homes in a low-income area may have access to different resources than a care home in a more affluent area. Any differences between the care homes, backgrounds and experiences of participants were likely to produce different results, and thus may produce contrasting results to inform theory. For the purposes of this study, cases were selected on the basis of theoretical replication. Similarities within and across cases may indicate the construct validity and credibility of the study.

Care homes in Greater Manchester were purposefully sampled to aid theoretical replication. Care homes were approached that varied in size, provision of nursing care or not, type of care home, i.e. whether purpose built or refurbished house, and those in a high or low-income area, based on demographic area. Information on the Commission latter obtained Care was from the Quality website. https://neighbourhood.statistics.gov.uk/ and http://www.checkmyarea.com. This enabled the exploration of the process of identity management within the context of different types of care home over time. A purposive sample is not representative and unlikely to meet the aims of generalizability typically associated with positivist research. Rather, purposive sampling of multiple cases has the potential to yield particularly rich data (Patton, 1990; Yin, 2010). Selection should aim to obtain a broad range of perspective on the subject to maximise the information provided (Yin, 2010). This includes sources that may provide contradictory information.

The aim was to obtain an array of purposefully sampled care homes in Greater Manchester, but there was also an element of convenience sampling involved. The study was ultimately limited to care homes that agreed to participate, and the resources of a solo researcher. Furthermore, as data collection occurred longitudinally across each care home, there was a compromise between the number of care homes recruited and the length of time spent in each one. Qualitative research typically relies on smaller sample sizes to achieve more in-depth data (Patton, 1990; Miles and Huberman, 1994). Therefore, a smaller number of care homes facilitated richer data over a longer period of time, but also limited the possibility of additional care homes being involved, which could have increased the variability in 'types' of care homes recruited. Further limitations of the study are discussed in Chapter Seven.

#### 4.2. Negotiating access

Initially, letters of invitation, including participant information sheets (PIS) (see Appendices 5-11) were sent to managers of purposefully sampled care homes in Greater Manchester. Twenty three care homes were approached to participate; the care homes varied in size, location, whether purpose-built or not, and ownership (e.g. whether privately owned or run by a council/charity). Three agreed to participate over the course of the study. The three care home managers who responded positively were contacted to discuss the study further and arrange a convenient time to meet with other members of staff and, where possible, residents. Non-responders were followed up with a telephone call after a grace period of about two weeks (as specified in the invitation letter), to determine whether they had received and read the information, and would like to participate or would allow their care homes to be used as case study sites.

Some care home managers failed to provide a response to the request to participate. For other care homes, it became apparent after speaking to the managers that the majority of residents would not be eligible to participate, and were not viable options to be included in the study. Other care home managers that declined the opportunity to participate in the study mostly mentioned concerns about the time constraints on members of staff. This was despite assurance that involvement of individuals was purely voluntary and observations would be unobtrusive. An additional reason given for declining to participate was the potentially negative repercussions of the study. Managers and some care staff often cited the negative representations of care homes in a recent Panorama documentary (British Broadcasting Company, 2014) and local media at the time of recruitment (Brindle, 2013; Slater, 2015; Taylor, 2015). Although I assured the care home staff that the aim of the study was not to uncover poor practice and further the negativity surrounding long-term care, but was purely unbiased and exploratory, this did not suffice to obtain agreement to participate.

#### 4.3. Sampling and recruitment of participants

Yin (2009) emphasises that data sources should be related to the research questions, and therefore the sources of data were chosen on the basis that they would provide relevant information to meet the aims and objectives of the study. It is important to include the perspectives of multiple stakeholders in the transition and identity management process because individuals may have different experiences, and perceptions of how the transition to a care home impacted the residents' sense of self. Therefore, residents, their significant others, and members of staff who met the inclusion criteria (Appendix 11) were invited to participate. These participants could each provide information about the experience of the transition to a care home and subsequent identity management. As discussed in Chapter Three, these groups of stakeholders (residents, their significant others, and care home staff) served as embedded units of analysis. This allowed for the complexity between the boundaries of the phenomena under study (identity management in care homes) and the context of the care home. Using embedded units of analysis enabled an exploration as to

whether different stakeholders held different perspectives, as well as the interactions between these stakeholders.

Most participants were recruited via convenience sampling, with opportunistic interviews and/or observations. Some participants were selected purposefully because other participants informed me that they had an interesting, relevant or unusual story to tell. The recruitment procedure is outlined in Section 4.3.1.

There was no pre-determined sample size for this study. It is often difficult to determine an adequate sample size in qualitative research, as too few participants could yield data of limited depth, and too many is likely to produce superficial data (Sandelowski, 1995). Qualitative researchers must justify the presented sample size in terms of quality of data, with all participants being equally represented in the findings (Cleary et al., 2014). The number of participants ultimately depends on "what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility" (Patton, 1990: 311). Participant recruitment and data collection ceased once data saturation was reached; when no new themes emerged from data analysis within that case (Morse, 1994; Trotter, 2012). The concept of data saturation is associated with the theoretical sampling of grounded theory (Glaser and Strauss, 1967), but has been utilised in other qualitative studies that did not use grounded theory (Carlsen and Glenton, 2011). Data saturation enables the development of Geertz's "thick description" (Geertz, 1973), and a small number of in-depth interviews or field notes may produce sufficient, relevant information for analysis (Cleary et al., 2014).

The inclusion/exclusion criteria for all three groups of participants are illustrated in Table 3. Briefly, residents who did not have capacity to consent were not included in the study, but may have been mentioned in field notes to aid the description of a particular event. I did not have access to resident's records and was unsure of which residents were diagnosed with a severe cognitive impairment or learning disability, and therefore did not know who could give consent to be interviewed. Members of staff in the care home were asked to identify residents who conformed to the inclusion criteria, and were then approached to participate. Issues of consent are discussed in more detail in Section 4.5.3. Some members of staff also pointed out

residents or significant others who had particularly 'interesting' stories, either regarding their personal lives or the transition to the care home. Where possible, I endeavoured to include these individuals as well. The minimum age of 65 years was selected on the basis that this was the accepted definition of an older person (World Health Organisation, 2015).

The study was open to all types of staff within the care home, not just managers or staff that performed hands-on care. Also, the term 'significant others' was initially used in the study to describe friends and/or family members who had a relationship with the resident, and who visited them in the care home. Relatives are not the only source of meaningful interaction, and some residents may have received visits from friends who could engage in equally meaningful interactions with the resident. Some residents may not have had relatives who visited them, and relied on friends. However, as this study progressed, it became evident that the only visitors residents received were family members, which is why the term 'relatives' is used predominantly throughout the thesis.

<b>Residents:</b> older people who permanently reside in the care home.		
Inclusion criteria	Exclusion criteria	
Aged 65 years or older. No upper age limit.	Under the age of 65 years	
Resident in a care home.	Is not a resident in a care home	
Have experience of a transition to long- term care and are able to recall these experiences.	Does not have experience of a transition to long-term care or is not able to recall these experiences.	
Must have the capacity to consent to participate.	Residents do not have the capacity to consent to participate in the study.	
English speaking and have a sufficient level of literacy to read through and understand the information and consent forms.	Does not speak English, and/or have the level of literacy required to understand the information and consent forms.	

Table 3. Inclusion and exclusion criteria for participants

Are only in the care home for a limited
period of time (e.g. for respite or
rehabilitation), with the intention of
moving back home

**Significant others:** individuals who are important to the resident, and who visit him or her in the care home. This includes family members and friends.

Inclusion criteria	Exclusion criteria
Is a relative/friend/informal caregiver or next of kin for a resident in the care home who visits the resident in the care home	Is not relative/friend/an informal carer or next of kin for a resident in the care home who visit the resident in the care home
Is able to answer questions about the residents' personality and features of his/her identity.	Is not able to answer questions about the residents' personality and features of his/her identity.
English speaking and have a sufficient level of literacy to read through and understand the information and consent forms.	Does not speak English, and/or have the level of literacy required to understand the information and consent forms.

**Staff:** Members of staff in the care home who have regular contact with the residents. Interviews with members of staff were conducted while the staff were on duty at the care home.

Inclusion criteria	Exclusion criteria
Managerial or care/nursing staff at a care home facility.	Is not managerial or care/nursing staff at a care home facility.
Works with residents who are new to the care home, or adapting to life in a care home.	Does not work with residents who are new to the care home, or adapting to life in a care home.
English speaking and have a sufficient level of literacy to read through and understand the information and consent forms.	Does not speak English, and/or have the level of literacy required to understand the information and consent forms.

### 4.3.1. Recruitment

Before approaching individuals to participate, I spent a couple of days in each care home discussing the research with residents, their relatives, and staff members. This was to allow people to feel comfortable with my presence in the care home and to give them the opportunity to ask questions and voice concerns prior to the data collection process. Before approaching family members to participate, I initially discussed the latter's participation with the residents first, where possible. Some residents did not want to be interviewed, but were happy for me to talk with their significant others.

Residents, staff, and relatives were verbally made aware of my presence in the care home and of the study, either by myself, a member of staff, and sometimes by the care home residents. To supplement this, I displayed information posters about the study, where possible (Appendix 15). These posters briefly explained who I was and what the study was about, and that I would be engaging in participant observations and making field notes. Participant information sheets (PIS) were kept in the main offices at each care home, and I kept copies of information sheets with me whenever I visited a home. Verbal and written information encouraged potential participants to contact me if they had any questions or concerns about the study.

Participant recruitment was a staged approach. Firstly, either myself or members of staff in the care homes informed others of the study, and distributed PIS to those who met the inclusion criteria. Secondly, if people expressed an interest in participating, they contacted me directly using the contact details on the information sheet or spoke to me whilst I was in the care home. I then confirmed that they met the inclusion criteria, acquired consent to participate, or organized a time to meet if they were unable to be interviewed at that time.

Any participant who met the inclusion criteria (Table 3) was approached to participate. Some members of staff pointed out residents who had experienced 'interesting' transitions to the care home, or who the staff thought would be willing to engage with the study. If those individuals met the inclusion criteria, they were also approached to participate. Recruitment of residents was restricted by the high proportions that were unable to consent. The majority of residents across the participating care homes experienced severe cognitive impairments, and could not consent to participate in the study. Recruitment was restricted to the minority of residents who did have capacity to consent.

All members of staff and relatives who met the inclusion criteria were approached to participate in the study. Discussed further in Chapter Five, many members of staff felt too restricted by time to consent to be formally interviewed. Staff typically either consented to a short interview when on a break, or agreed to have our 'on the fly' conversations during their daily tasks to be noted in field notes (see Section 4.4). Similarly, all eligible relatives and visitors were approached to participate and were made aware of observations. The recruitment of relatives was dependent upon them visiting the care home. If members of staff were aware of a pending visit from a relative, I endeavoured to visit the care home in order to approach the relative to participate. If the visit occurred during a period when I could not also be present, staff were asked to provide a PIS to that relative, and request that they contact me if they were interested in participating, in order to arrange an interview.

# 4.4. Data collection

The triangulation of data collection methods can improve the quality of qualitative research and produce robust, in-depth "thick descriptions" of a phenomenon (Geertz, 1973; Shenton, 2004). This study benefits from the combination of qualitative semistructured interviews and a series of observations with residents, their relatives and members of care home staff, conducted longitudinally across each case (the care homes). Developing a reflexive, iterative process between data collection and analysis continuously connects the data with emerging insights, leading to a more refined understanding of the phenomenon under study (Srivastava and Hopwood, 2009). Furthermore, Yin's (2009) case study approach advocates the use of multiple sources of evidence, and the use of interviews and observations reflect two of the six evidentiary sources Yin suggests (Yazan, 2015). The triangulation of data collection methods conducted longitudinally within and across multiple cases enables the co-construction of shared meanings of the concept of identity, via a hermeneutic circle (Guba and Lincoln, 1989), discussed further in this chapter. The rationale behind the chosen methods and how they were actuated are discussed below. As previously stated, due to the exploratory nature of the study, the aforementioned theoretical propositions were used as a loose guide, and data collection was predominantly guided by the iterative nature of data collection and analysis.

The care homes allowed me to enter their premises as many days per week as I required. Though managers and care staff stated that I did not need to inform them of my arrival, out of courtesy I generally left a message with a member of staff informing them of when I planned to enter the care home. The following sections explicate the data collection methods in light of the ontological, epistemological and methodological perspectives outlined in Chapter Three.

#### 4.4.1. Interviews

Interviews are used to explore participants' beliefs or thoughts about their experiences of a phenomenon (Murphy and Dingwall, 2003). According to Charmaz, (1995: 54), interviews aim to "...represent the person's view fairly and to portray it as consistent with his or her meanings." However, the notion of an interview capturing a participant's genuine perspectives is often considered a romanticised view of the reality of conducting qualitative interviews (Miller and Glasner, 2011;Silverman, 2011). Rather, they do not strive to achieve a "true" reflection of reality, but instead access the meanings people attribute to their social worlds (Miller and Glasner, 2001: 1133). Interviews are a unique social encounter, within which explanations for behaviour or perceptions are located in that individual's point of view within a particular context (Hermanowicz, 2013). Using qualitative interviews in this study can help to uncover residents' perspectives on their changing or stable sense of identity following the transition to a care home, as well as including the perspectives of their significant others and members of care home staff.

Semi-structured interviews are a more informal approach than structured interviews, which rigidly adhere to a prescribed interview schedule. Semi-structured interviews are particularly useful in qualitative studies that aim to address exploratory questions, as this study aims to do. Typically, the researcher establishes a topic guide prior to entering the field that are based on the literature and/or early observations

(Hancock *et al.*, 1998; Murphy *et al.*, 1999; Al-Busaidi, 2008). Semi-structured interviews combine structure and flexibility. The order, content, and pace of the interviews can be amended to suit the participant, and enables the researcher to respond to comments raised during the interview (Legard *et al.*, 2003).

For this study, a topic guide was constructed prior to entering the care home. Questions were initially based on the identity and care home literature, and the aforementioned theoretical propositions. Questions encouraged participants to discuss their experiences of the transition to the care home, and their subsequent adjustment. Participants were also asked questions about the resident's personal biography, and any important elements that they perceived to have changed or stayed the same following the transition to a care home. For the final topic guides, see Appendices 20-22. Although qualitative research requires substantial planning, it is important to keep a flexible research strategy (Green and Thorogood, 2014). Questions were iteratively amended following the initiation of the data collection period in light of responses from other participants or observations. During interviews, the order of questions changed, as well as the wording, and new questions were added ad hoc based on responses from the participant or observations made within the care home. This approach ensured that themes and topics were discussed that were relevant to the participants, and not solely based on the a priori theoretical assumptions that instigated the research.

Interviews limit the amount of naturally occurring data in the environment and can erase context from consideration. By nature, narratives unearthed during interviews must be partial in length, as no narrative can be long enough to adequately represent the individual's whole perspective (Miller and Glasner, 2011). To counter some of these criticisms, semi-structured interviews were used alongside observations. Conducting observations enables the researcher to include contextual information in the overall analysis, and to discuss observations during interviews, or attempt to observe behaviour mentioned in interviews (Ritchie, 2003; Guest *et al.*, 2013). This serves to contextualise the data, and make comparisons between comments made in interviews and behaviours observed during observations.

Members of staff in the care home were typically interviewed while they were on

duty, often during a break. One member of staff arranged to meet shortly before her shift began. Significant others were interviewed within the care home; some arranged a particular time to meet that was most convenient for them, and others agreed to be interviewed while they were visiting the resident. Residents who agreed to participate were given the option of being interviewed in their own bedrooms, or in the communal areas, depending on where they felt most comfortable. Where possible, all participants were given the option of conducting the interview in a private spare room or wherever else they felt comfortable in the care home. During observations, I also made field notes on informal conversations. Participants were regularly reminded that notes would be made on observations and conversations. Interviews were audio recorded and later transcribed verbatim by myself. Participants could request that the audio recorder be turned off at any time. Interviews lasted between ten minutes to two hours and were largely dependent upon how comfortable the participant felt to continue being interviewed.

# 4.4.2. Participant observation: an overview

"...a good way to learn about any of these worlds is to submit oneself in the company of the members to the daily round of petty contingencies to which they are subject".

(Goffman, 1961: 7)

Interviews are generally the preferred method of data collection in healthcare (Merrell and Williams, 1994), but Silverman (Silverman, 1998; Green and Thorogood, 2014) argues that qualitative interviews have been overused. Even indepth qualitative interviews do not achieve an exhaustive account of a phenomenon, and neglect naturally occurring data and contextual information (Ritchie, 2003; Silverman, 2006). Observations can determine whether "what people say and do is the same as what they actually do" (Mulhall, 2003: 207), as individuals often forget or do not think to discuss particular issues in the confines of an interview. Also, certain elements of a phenomenon may only become salient through observations, as 'insiders' may be so accustomed to them, that they are not discussed in interviews. Observational methods can also provide insights in to relations between groups, captures the context of these interactions and addresses the influence of the physical

environment. Individuals' conception of reality is not directly accessible to 'outsiders', i.e. the researcher (Atkinson and Hammersley, 1994; Jorgensen, 2015). But by being engaged in the environment and with subjects in the day-to-day experiences in particular situations, the researcher can ask about their feelings and interpretations (Jorgensen, 1989; Atkinson and Hammersley, 1994; Jorgensen, 2015).

Observational methods reflect the ontological, epistemological and methodological perspectives outlined in Chapter Three. Observations could provide in-depth, context-rich information (Patton, 1990; Silverman, 1998) on the significance of interactions and the co-construction of identity (Davetian, 2010; Blumer, 1969). Furthermore, an aim of observational research, such as participant observation, is the interpretation of meanings and reality from the standpoint of the observed (Atkinson and Hammersley, 1994), which is particularly pertinent from a social constructivist perspective (Lincoln and Guba, 1985). Observational methods also help to enhance the credibility of the study (Lincoln and Guba, 1985).

There is some debate over definitive classifications of ethnography and participant observations. It is difficult to make clear distinctions between the two design typologies (Green and Thorogood, 2014), as the division between them is unclear. Both fall under the concept of 'naturalism', whereby phenomena are studied in their natural environment (Green and Thorogood, 2014), and based within interpretivist and constructivist paradigms, given the significance placed on shared meaning-making through social interactions (Atkinson and Hammersley, 1994). The terms 'ethnography', 'fieldwork' and 'participant observation' are often used interchangeably within qualitative research (Delamont, 2007). The term ethnography is inclusive, with fieldwork and participant observation serving as more descriptive techniques for data collection (Atkinson and Hammersley, 1994). Fieldwork refers to the data collection phase of a study, and participant observation describes a mixture of observation and interviewing. Thus for the purposes of this study I shall use the term 'participant observation' to describe the method adopted.

As discussed, this study is exploratory. According to Jorgensen (1989), participant observations are appropriate for exploratory studies, and generally should meet certain minimal conditions:

- "The research problem is concerned with human meanings and interactions viewed from the insiders' perspective;
- The phenomenon of investigation is observable within an everyday life situation or setting;
- The researcher is able to gain access to an appropriate setting;
- The phenomenon is sufficiently limited in size and location to be studied as a case;
- Study questions are appropriate for case study; and
- The research problem can be addressed by qualitative data gathered by direct observation and other means pertinent to the field setting".

(Jorgensen, 1989: 13)

The current study meets each of these criteria, as the nature of identity management is largely based on social interactions that are observable in an everyday life setting, i.e. the care home, to which I am able to gain access. Furthermore, a smaller sample of care homes enables the phenomenon to be studies as case, for which the study questions are appropriate (discussed in Chapter Three). Finally, the aims of the study can be achieved by collecting qualitative data obtained through observations and the aforementioned semi-structured interviews.

The role of the researcher in observational research lies along a continuum (Gold, 1958). This ranges from: 'complete observer' who maintains a distance and is concealed from those being observed; 'observer as participant' where the researcher undertakes observations whilst engaging in activities of the group, who is aware of the research activity; 'participant as observer', who is a member of the group being observed, and the group is aware of the research activity; 'complete participant' is a member of the group who observes from a concealed role as researcher (Gold, 1958). These stances vary in their ethical and practical implications. For the purposes of the current study, I adopted a stance more similar to 'observer as participant', but the form of observations conducted in this study varied between participant and non-

participant observations. I am not a trained nurse and do not have any caring qualifications, so, I participated in the daily life of the care home where possible, and observed without participation in the situations when I could not engage in an activity. The nature of my participation was largely limited to assisting with tea breaks, occasionally distributing meals at mealtimes, assisting with organised activities such as bingo, and on one occasion, moving furniture. The majority of my observations were non-participant, i.e. I observed the environment and did not directly contribute to activities. During observations I made field notes on interactions between residents, members of staff and significant others who visited the care homes. More information on field notes will be discussed below in Section 4.4.3.

Observations can be structured or unstructured (Pretzlik, 1994; Mulhall, 2003). Structured observations are typically used in positivistic research, whereby the researcher attempts to remain a passive observer so as not to "contaminate" the data (Mulhall, 2003). Unstructured observations are a key tool in anthropological and sociological research, and are used to understand and interpret behaviour. Mulhall (2003) considers unstructured observations to be underexploited within nursing research. They can include formal interviews and notes from informal conversations, so as to compare what people say with what they do (Mulhall, 2003), which complements the individual semi-structured interviews in this study.

# 4.4.2.1. Critiques of observational research

Observational research is not without its criticisms. The Hawthorne effect will always be a concern during observational research, whereby observed individuals who are aware of the observations will modify their behaviour. However, some believe that the Hawthorn effect is overemphasised within participant observation (Mulhall, 2003). While participants may modify their behaviour initially, eventually they are likely to revert to their usual behaviours (Frankenberg, 1980; Mulhall, 2003). Hence observations conducted longitudinally have the additional benefit of allowing for this acclimatisation period, until the researcher and participants get used to one another, and any modified behaviour falls back to type. Observational data is also more subject to interpretation than formal recorded interviews (Mulhall, 2003). Though participant observations focus on individuals' experiences of phenomena from the standpoint of those 'insiders' (Jorgensen, 1989), it is nonetheless expressed through the interpretation of the 'outsider', i.e. the researcher. This calls into question the extent to which the researcher brings their own predispositions and assumptions into the field. These predispositions may influence how the researcher makes field notes, and subsequently interprets them.

To address these criticisms, researchers can use a reflexive approach (Green and Thorogood, 2014). It is of course impossible for the researcher to be completely immersed in an environment so as to observe 'true' behaviour, but reflexivity enables the researcher to consider how his or her assumptions and behaviour can influence the study (Watt, 2007). Following any observation or interview I wrote reflexive notes. The reflexive notes were not data per se, but my own reflections on my role as a researcher, and initial thoughts on the issues relating to identity management that could guide my analysis. The value of reflexivity and how this was achieved is addressed in section 4.6.5.

# 4.4.3. Field notes

I wrote field notes during every period of observation, and also made notes after interviews if necessary. Field notes are "*are gnomic, shorthand reconstructions of events, observations, and conversations that took place in the field*" (Van Maanen, 1988 pp. 223–4, cited in Wolfinger, 2002).

There are two strategies for writing field notes, though they are not mutually exclusive (Emerson *et al.*, 1995). First, the 'salience hierarchy' refers to notes taken on events that struck the researcher as particularly noteworthy or interesting. Second, 'comprehensive note-taking', refers to where the researcher systematically describes everything within a particular period of time, and this can be done temporally. Many social settings and organisations have their own timetables (Hammersley and Atkinson, 1983), so structuring field notes according these timetables may help recall, and can help the researcher to develop an understanding of the phenomenon under study (Emerson *et al.*, 1995; Wolfinger, 2002). For this study, field notes were

a combination of salient events and comprehensive notes. I made field notes on any interactions between residents, staff and/or significant others that occurred within the care home; particularly on interesting or unusual events or occasions identified in literature as relevant to the experiences of long-term care, such as mealtimes or organised activities.

Field notes were typically written in chronological order. It was also important to make notes on seemingly innocuous events, or situations where apparently nothing was happening, such as when residents were sitting in a lounge area and 'doing nothing' or 'just' watching television. Including notes on 'nothing' provided a more complete and accurate picture of life in a care home and enabled the juxtaposition between more obviously eventful situations. Field notes were usually written during observations or immediately after a period of observation was completed. If there was a lull in activity or during a break, I would write notes in a more private room before continuing with data collection, in case my recall later was impaired.

Some participants did not wish to be formally interviewed and audio recorded; many did not provide a reason, but indicated that they were somewhat intimidated by the notion of being recorded or simply found it easier to talk outside the remit of a formal interview. They were, however, happy for me to write notes on our discussions, including quotes. As discussed in the section on ethics (Section 4.5.3), participants were regularly made aware that their comments would be noted and used in the study, unless they expressly stated that they did not wish to be included or have a particular quote used.

Field notes made immediately after interviews were also useful in maintaining some contextual information to ensure the context was taken in to consideration during analysis. Such information allows the researcher to note thoughts about the interview, and any relevant information that occurred just before or just after the interview began (Arthur and Nazroo, 2003).

## 4.4.4. Longitudinal research

This study was conducted longitudinally, over approximately one year. Serial interviews and observations have several advantages over data collected at a particular time. The latter takes a 'snapshot' of individuals' perceptions at one time (Pettigrew, 1990), whereas longitudinal interviews focus on individuals' narratives and lived experiences of a phenomenon within a particular context over time (Calman et al., 2013). Qualitative longitudinal interviews are growing in popularity within healthcare research (Carduff et al., 2015), and studies have established that they are useful in exploring transitions in care (Calman et al., 2013), such as mapping the cancer journey (Calman et al., 2013) and transitions in aged care (Miller et al., 2015). As people change, new ideas, themes and perceptions may emerge as well (Hermanowicz, 2013). The literature review in Chapter 2 highlighted eight studies that benefited from a longitudinal approach (Golander, 1995; Tester et al., 2004; Surr, 2006; Moss and Moss; Riedl et al., 2013; Oosterveld-Vlug et al., 2014; Anbäcken et al., 2015; Heggestad and Slettebø, 2015), though the length of these studies varied greatly. A longitudinal approach can be useful in exploring the concept of identity in care homes over time, as residents' interpretations of their experiences may change over time due to changes in the environment or social interactions and relationships.

A longitudinal study lends itself to the development of a hermeneutic circle, whereby the researcher simultaneously collects and analyses data (Glaser and Strauss, 1967; Strauss and Corbin, 1994; Hermanowicz, 2013), using that data, and reflections on it, to inform subsequent data collection. A hermeneutic circle describes a circle of information between participants, and the process of understanding the whole through movement back and forth between its parts. Viewpoints and themes are shared during data collection to enable the co-construction of meaning. A hermeneutic circle is a main component of constructivist research (Guba and Lincoln, 1989), but is a useful approach within qualitative research in general, particularly across multiple cases. The concept of identity within a care home can be better understood by iteratively using data from interviews or observations to inform subsequent interviews and observations. During interviews I introduced initial thoughts and actions witnessed during observations. As participation progressed in each care home, new observations shaped further interviews and discussions, and vice versa, thus informing data collection and analysis (Rodwell, 1998). Any similarities or differences between viewpoints were identified and discussed, including viewpoints within and across each care home to determine whether perspectives differed, and why.

# 4.5. Analysis

#### 4.5.1. Introduction

The findings of the study were analysed using Framework Analysis (FA), within and across the cases. Although Yin (2009) describes five analytic techniques: pattern matching; explanation building; time series analysis; logic models; and cross case synthesis, he does not go in to much depth or offer much guidance regarding the analysis of case study data. Framework Analysis was developed by (Ritchie and Spencer, 1994) within social policy, as a pragmatic attempt at investigating real-world phenomena (Ward *et al.*, 2013). It has since become popular with healthcare researchers (Ward *et al.*, 2013). Briefly, FA enables the thematic, or case-based, systematic analysis of multiple sources of data, but is flexible enough to accommodate an iterative approach to analysis (Smith and Firth, 2011; Gale *et al.*, 2013; Ward *et al.*, 2013).

Given the exploratory nature of the present research question, FA was considered to be an appropriate form of data analysis. Furthermore, as FA enables the exploration of patterns within the data, it was particularly pertinent for Yin's (2009) pattern matching technique.

Theoretical propositions were used as a loose guide during data collection and analysis. Given the iterative nature of data collection and analysis, this allowed for emergent themes to be incorporated in the analytical framework.

## 4.5.2. Framework analysis

Framework Analysis is considered to be a systematic and rigorous approach, more so than Thematic Analysis (Ward *et al.*, 2013), as there are five distinct, interrelated stages in FA (see Box 1) that provide a clear structure. This structure contributes to

the audit trail of decisions made throughout the process, ensuring transparency of how results were obtained (Lincoln and Guba, 1985; Shenton, 2004; Smith and Firth, 2011; Ward et al., 2013). Yet FA also lends itself to an iterative approach between data collection and analysis, with Spencer et al. (2003: 199) stating that: "although there will be a stage dedicated to analysis, the pathways to forming ideas to pursue, phenomena to capture, theories to test begins right at the start of a research study and ends while writing up the results". This combination of structure and flexibility was pertinent for the current study. First, a structured approach helped to organise the large volume of qualitative data produced. Second, the structure of analysis served to create a clear audit trail so as to avoid confusion and ensure that findings and interpretations are grounded in the data (Lincoln and Guba, 1985). This improves the overall quality of the data (discussed further in Section 4.6). Third, the iterative nature of FA complimented the dialectical epistemology and use of a hermeneutic circle between analysis and collection of data in the current study. Fourth, FA allowed for the analysis of multiple types of data, including interview transcripts and field notes (Ritchie and Spencer, 1994; Gale et al., 2013), which corresponded to the aims and objectives of the current study to include semi-structured interviews and observational data. Finally, data can be analysed within and across cases (Ritchie and Spencer, 1994), which also reflects the aims and objectives of the current study.

# Box 3. Stages of Framework Analysis. Adapted from Ritchie and Spencer (1994) and Ward *et al.* (2013)

1. Familiarisation

Immersion in the data. Read complete transcripts and field notes

# 2. Identify a thematic framework

Initial development of a coding framework developed through a priori issues and familiarisation stage

# 3. Indexing

The process of systematically applying the thematic framework to data. Changes made as necessary to reflect the data

**4. Charting** Using headings from thematic framework to create charts of data

**5. Mapping and interpretation** Searching for patterns and explanations in the data Researchers have varied slightly in how each stage of FA is performed, or vary semantically across the stages (Furber, 2010; Gale *et al.*, 2013). Additionally, each stage might not occur in a linear manner, and may involve repetition of certain stages. Throughout the current study, each stage occurred iteratively with regular inspection of the original data, to improve the dependability of interpretations.

The data was coded using NVivo, as well as paper and post-it notes; all of which are valid methods for conducting FA to enhance flexibility (Wong, 2008; Ward *et al.*, 2013). Computer-assisted data analysis software such as NVivo is useful for storing and organising large amounts of data (Weitzman, 2000; Wong, 2008). NVivo is also particularly useful for use with FA, as the researcher can code data and categorise those codes into larger themes (Wong, 2008). NVivo also allows the researcher to save notes on emerging ideas or themes, separate from the analysis (Zamawe, 2015). The computer and paper-based forms of analysis were used in tandem. Transcripts and field notes were initially coded and placed in to preliminary themes using NVivo. The codes were then printed out and physically moved in to thematic categories, which were colour co-ordinated. The following sections illustrate how each stage of FA was completed.

# Familiarisation

Familiarisation was facilitated by conducting all the interviews and observations myself. I also transcribed all interviews. Audio files were listened to multiple times, and transcripts and field notes were read repeatedly to immerse myself in the data and become familiar with it (Ritchie, 2003), in order to appreciate the wholeness of the interviews and field notes prior to sectioning them off in to themes (Ward *et al.*, 2013). This process was conducted iteratively throughout the research period. Any emerging ideas were noted.

# **Identifying thematic framework**

A preliminary 'working' framework was developed from themes outlined in the literature and data collected early on in the process. As data collection progressed, the framework was amended to more accurately reflect participants' perceptions and themes as they emerged through the hermeneutic circle.

I read the data line by line and applied a code that described a salient element of the sentence or passage (Gale *et al.*, 2013). Codes can refer to emotions, values, or substantive, descriptive things such as behaviours (Gale *et al.*, 2013). Codes can also be inductive or deductive; the nature of FA combines a deductive pre-defined coding framework with a more flexible, inductive approach that enables the framework to be amended during the iterative process. While initial codes were based on the working framework, these were amended as necessary to more accurately reflect the concept being described and further ground interpretations in the actual data (Lincoln and Guba, 1985). 62 codes were identified. The coding framework is presented in Appendix 23.

## Indexing

The codes were then grouped in to themes, which created the initial working framework. The framework was then applied to subsequent data, where themes and codes were developed and refined. Relationships between themes were explored, including similarities and differences between themes, while regularly referring back to contextual information in the original data to ensure correct interpretations.

#### Charting

Themes were reduced and summarised in order to be more easily understood. Charting the data involves creating a Microsoft Excel spread sheet that contains descriptive summaries of themes from each transcript (Gale *et al.*, 2013). This often includes illustrative quotes from participants.

While FA could be considered to be reductionist because data is charted and summarised, this is not different from most other forms of qualitative analysis, and is essential for large volumes of data. The main difference is that FA allows for this reduction to be observed via a clear audit trail. The decisions made throughout the analytical process can be observed during each phase (Ritchie and Spencer, 1994).

## Mapping and interpretation

At this stage, key themes were interpreted in light of the data as a whole (Ritchie and

Spencer, 1994), by comparing and contrasting data. This is similar to pattern matching and explanation building techniques, described by Yin (2009).

Throughout this process, it was important to engage in 'member checking' with the participants to check that their perspectives were interpreted and included as accurately as possible (Lincoln and Guba, 1985). This can enhance the confirmability and dependability of the data (Shenton, 2004), as findings are consistently linked back to the original data and the participants. Member checking also allows participants to engage in the process of data analysis, and to determine whether the researcher has accurately interpreted them (Rodwell, 1998). Where possible, I provided typed summaries of individuals' data. The length of these summaries varied depending on the volume of data retrieved from a participant. However, residents often found the summaries difficult to read due to poor eyesight, and some found the idea of reading the summaries overwhelming or intimidating. Most members of staff did not have the time to read through documents. Therefore, I often provided oral summaries of the data they provided, and invited comments. The summaries tended to include pertinent comments they had made, or observations, and my interpretations of these data. However, most relatives did not re-visit the care home during the study period for us to discuss their comments. Only one relative revisited, and I provided an oral summary. There were no instances of participants disagreeing with my interpretation or initial analysis of the data they had provided.

For multi-case case studies, researchers will either rely on within-case or cross-case analysis (Yin, 2009). First, the responses in a single case, i.e. within one care home, were analysed to highlight any differences or patterns in their responses (within-case). Second, responses from different care homes were analysed to compare patterns in responses (cross-case). Initial themes within each case were compared and contrasted with one another. It became apparent that the majority of the themes were emerging across all care homes, with only minor differences in prevalence or interpretation, hence why the findings are structured and discussed in relation to the cross-case analysis.

The flexible approach adopted for this study, as well as the working methods, raised some ethical issues, which will be discussed in the following sections.

# 4.5.3. Ethical considerations

Ethical approval for the study was obtained from the University of Manchester, and Northampton NRES committee (reference number: 12/EM/0431), which was a flagged ethics committee due to the potential involvement of vulnerable older people. Approval was also obtained from the NHS Research and Development (R&D) department (see Appendices 3 and 4 for confirmation of ethical approval from the Research Ethics Committee (REC), and NHS R&D).

This study involves older people who reside in care homes and their families, and explores a potentially emotive topic. There were a number of issues to address to ensure that the study was conducted as ethically as possible

#### 4.5.3.1. Consent

Participants should not be made to feel coerced to engage in research, and must have a full understanding of the study and the implications of their participation (Green and Thorogood, 2014). According to Homan (1991: 71), the concept of 'informed' includes "all pertinent aspects of what will happen are disclosed to the participant", and they can understand that information. To achieve 'consent', the participant must be able to make rational decisions and judgements about their participation, and that participation must be voluntary and free from influence or coercion (Homan, 1991). As the present study did not include a formal assessment of capacity, members of care home staff were consulted regarding which residents had the capacity to consent to participate.

All potential participants were provided with relevant information about the study so that they could make an informed decision about whether or not to participate. This included the contact details of the researcher, if they had any questions. Participant information sheets (PIS) were developed for each group of participants (see Appendices 8-10) following the advice of the Research Ethics Committee, which suggested one form per stakeholder group, not one general PIS. The care homes were provided with multiple copies of each PIS to be displayed in their offices and distributed to potential participants when possible. Residents were given as much

time as they needed to decide whether or not to participate, to give them time to consult their families about the study if desired.

During the initial introductory period, prior to formal data collection, I introduced myself to people who were in the care home and explained why I was there, as some individuals might not know whether they were talking to me as a visitor or researcher. I sat and spoke with potential participants, often engaging in informal conversations. It was important that they felt comfortable with my presence in the care home, and that they felt their involvement was meaningful. I aimed to continuously verbally and visually identify myself as a researcher, by wearing a University of Manchester lanyard and ID, smart-casual clothing, and carried a large, brightly coloured field notebook.

After the initial introductory period I introduced the PIS to those potential participants who met the inclusion criteria (Appendices 8-10). I went through the information for those who wanted me to, as some residents had visual impairments and needed assistance understanding the information. Participants were given the opportunity to ask further questions if necessary and were regularly reminded that participation was voluntary and they were free to withdraw at any time. This was also included in the written information provided. Those who were happy to be interviewed were then asked to sign a consent form (Appendices 12-14), which I also went through with them before they signed. Participants could decline to speak to me at a particular time, for instance if they felt unwell, but could agree to be interviewed at a later date.

Information about the study, and specifically about the observations, was also provided via posters displayed in communal areas in the care homes (Appendix 15). Individuals could opt out of observation; either all observations, or particular observations. Anyone who opted out of observations would not have been included in field notes. The nature of the care home environment is often particularly busy, so it may not be possible to gain written consent from all parties without disrupting care. Ethically, it was important to be as non-disruptive as possible to ensure that residents' care is not affected by the study. In addition, requesting written consent at the time of the observation may also disrupt the particular event or interaction, and this influence the situation and, in turn, the data. Individuals who wanted to opt out of observations could do so by speaking to myself, or a member of staff at the care home who would relay the information to me, or via an "opt-out" form (Appendix 16) that were either left in communal areas alongside the PIS, or in the care home manager's offices.

The opt-out process could have been problematic, as individuals may not have received the information about the study or did not have the opportunity to request to withdraw. Therefore it was important to carefully manage the opt-out procedure and ensure that all individuals were aware of their rights to opt-out throughout the data collection process. Consequently, I was motivated to regularly remind all individuals involved in a particular observation period that I was to be making notes, and that they could decline to be involved. Nonetheless, no participants requested to opt-out of observations or have any data collected during an observation removed.

Those with cognitive frailty but with the ability to provide informed consent could still participate. There is considerable debate over how practical it is to obtain informed consent, particularly within the context of a care home. People may understand the information differently, or say that they understand when in fact they have misunderstood something about the study. Participants may also change their mind over time, or need reminding of the aims of the research. Informed consent within the context of a care home is an ongoing process, one that is continuously negotiated throughout the study (Madjar and Higgins, 1996). Therefore, I used process consent, whereby consent was renegotiated during each interaction (Brown Wilson, 2011). I regularly approached each participant and discussed their consent to be involved in the study, to ensure that they continued to wish to be involved. Residents with severe cognitive impairment who were unable to provide informed consent were excluded from interviews, but were included in observations for contextual purposes, i.e. if they were central to observations involving other, consenting participants. But in order for those residents to feel included in the research process, I met and conversed with them when I visited each care home.

#### **Emotional responses and after care**

It may be upsetting or overwhelming to be approached to participate in a study following a potentially emotive move to a care home. Some participants may feel uncomfortable with discussing such issues in depth.

Throughout the research process participants were made aware that the interviews were as flexible and non-invasive as possible, and that their participation was voluntary and they were free to stop the interviews at any time without repercussions. They did not have to answer all questions and could choose to answer certain questions at another time if they were uncomfortable. I have previous experience discussing emotive issues in a research and clinical capacity, and have a counselling qualification, so have the necessary skills to determine whether a participant was becoming too upset to continue or required additional support. Post-interview support was arranged if participants became distressed during the interview, which was either a trusted staff member, another resident, or a significant other, depending on the participants' preference. If participants did become distressed, interviews were paused and consent renegotiated, as outlined in the Distress Protocol (Appendix 7). There was a single instance of a resident becoming upset, who requested that the interview be arranged. In this case, the interview was stopped, and the Distress Protocol was adhered to.

It was stressed in the information sheet that the interviews were not an alternative form of counselling. Nonetheless, some residents may agree to participate in order to have someone to talk to, rather than a desire to be included in the study (Brown Wilson, 2011). I would use my judgement to determine whether that was the case. However, there were no instances of this occurring with any participant.

Participants may disclose sensitive information, such as suicidal thoughts. If this occurred, a member of staff at the care home would be informed so that they could implement the relevant policies. All participants were made aware that their responses would be kept confidential unless they stated something that suggests a risk to themselves or others. There were no instances of this occurring with any participant.

Responses could cause distress to the researcher. The supervisory team was available via telephone should I have needed to discuss any issues. I received regular supervisions to address any upsetting material. Though the study was solely conducted in the care home, with multiple people in the vicinity, there was also some risk of being a lone worker when conducting interviews in private rooms. In view of this, loan worker training was undertaken and the University of Manchester's lone working policies were adhered to.

# Privacy

When conducting formal interviews I attempted to maintain the privacy of participants by arranging a private room where we were not likely to be disturbed by other people. Participants may not feel comfortable answering questions in communal areas in the care home due to potentially sensitive topics, or if they wish to discuss particular individuals. Residents were also given the option of being interviewed in their own bedrooms, if they felt more comfortable. The majority of participants felt comfortable being interviewed in the communal spaces and were undeterred from discussing sensitive issues in those areas. Those participants stated that they preferred to remain in their "usual seat[s]" to conduct the interview, rather than walking to an alternative room, which would take time and effort.

# 4.5.4. Confidentiality and research governance

Identifiable information collected during the study was not shared in other situations, unless expressly required to do so for the safety of participants. This was made clear to all participants before continuing with any form of data collection, and was included in the PIS and consent forms.

In the development of a hermeneutic circle, it is necessary to discuss themes and issues that have arisen with other participants or in other contexts. If particular themes or topics come from the same care home, there is a possibility that providing detailed descriptions could identify participants. If confidentiality were breached then this could have had a negative impact on the relationship of trust established at the care homes, which might have affected future participation. Therefore, I opted not to use direct quotes in case they alerted them to the identity of other participants.

Instead, I discussed issues that were raised more generally and used minimal quotations. It was necessary to preserve sufficient detail to convey participants' meaning, but not too much that they were identifiable.

The care home managers and all participants were told, verbally and via information sheets, that if I witnessed any poor care or had any concerns about the safety of anyone in the research environment, that I had a duty to inform the care home manager. On the occasions that I was unsure about an issue I observed, I contacted the supervisory team to determine the most appropriate course of action.

All physical data, including written field notes and consent forms, was stored in a locked cabinet at the University of Manchester. Electronic files, including typed field notes and interview transcripts, were encrypted and saved to an encrypted hard drive, which was also stored in a locked cabinet.

Individuals' names were changed to pseudonyms and the names of the care homes were altered. If a participant mentioned the name of a place or other person that could potentially identify them, it was deleted from transcripts and field notes and replaced with a non-identifiable alternative.

# **Benefits of participation**

Some participants said that they found the interviews to be beneficial by allowing them to talk about their experiences of their transition to, and life in, a care home, and how they felt this impacted their identity.

Individuals may also feel pleased that an 'outsider' has taken an interest in their lives. Oakley (1981) found that her interviewees who had recently transitioned to motherhood had felt that the interview was a positive experience that afforded the opportunity to discuss their personal experiences and opinions. In the current study, many participants expressed their happiness at being made to feel important and valued throughout the research process. Those who had been involved in other studies in the past stated that other researchers ask their questions and then leave, without making participants feel valued. It is important to see the participant as more than a source of 'good data', and facilitate a reciprocal relationship. If I asked participants questions, I was happy to answer their questions of me.

The care homes were also provided with a report of the findings (Appendix 26). Participants deserve acknowledgement of their participation and evidence of their contribution. Further, the report may provoke care home managers and staff to improve certain areas of their care, and offer encouragement regarding elements they performed well.

#### 4.6. Quality in qualitative research and case study

There is much debate regarding the nature of quality of qualitative research. Qualitative research and case studies have been criticised for their apparent lack of rigor and generalizability (Yin, 2009; Crowe et al., 2011). However, qualitative research is a distinctive form of empirical inquiry, and issues concerning validity, reliability and generalisability are based on the quantitative, positivist tradition (Seale, 1999a). There is no absolute list of criteria for good quality qualitative research, and with controversy around whether there should be criteria for assessing the quality of qualitative research at all, researchers are faced with conflicting positions and advice (Seale, 1999b). Even Yin (2009) proposes quality criteria that are more aligned with a positivist stance. As Seale (1999b) argues, the "quality of research is not automatically determined by the imposition of generalised quality criteria, but such schemes can help sensitise researchers to the issues that a particular project may need address". Lincoln and Guba (1985) to proposed four "trustworthiness" criteria that paralleled a positivist, quantitative approach to quality assessment (see Table 4). These criteria are reflected by other authors, though they use different labels. Each of these criteria overlaps and share similar methods for satisfaction. The quality criteria will be discussed in the following sections, including how they were addressed in the current study.

Table 4. Quality criteria for qualitative research. Adapted from Lincoln and Guba (1985); Baxter and Eyles, (1997: 512); Reid and Gough (2000: 68); and Shenton (2004)

Criteria	Description	How to satisfy criteria
Transferability	Sufficient detail and	Purposeful sampling
	information is provided in	Thick description
	order for the reader to	
	determine whether findings	
	are applicable in other	
	settings.	
Dependability	Evidence that appropriate	Low-inference descriptors <sup>2</sup>
	methodological decisions	Multiple researchers
	have been made	Participant researchers
		External audit or reflective
		appraisal
Credibility	Authentic representations	Purposeful sampling
	and accounts of	Prolonged engagement
	experiences.	Persistent observation
		Triangulation
		Negative case analysis <sup>3</sup>
		Referential accuracy <sup>4</sup>
Confirmability	Results are linked to the	Audit trail products
	data and not the	Thick description
	researcher's own biases or	
	perspectives.	

# 4.6.1. Transferability vs. External validity

Some authors have argued that for a study to be of good quality, it must be replicable to confirm the findings (Seale, 1999b). Case studies have also been criticised for a lack of generalisability, despite not having the same statistical generalisability as survey studies. Transferability replaces the external validity associated with quantitative inquiries (Seale, 1999b; Seale, 1999a). Transferability refers to how applicable findings from one environment are to another (Rodwell, 1998). Similarly, Yin (Yin, 2009; Yin, 2010) advocates 'analytic generalisation', whereby the researcher demonstrates that the findings of the study inform a conceptual claim or propositions (i.e. the impact of the transitions to a care home on residents' sense of identity), and that the same propositions are still relevant when applied to a similar

<sup>&</sup>lt;sup>2</sup> Recording of observations that include verbatim accounts of what people say, rather than solely a researcher's interpretations (Seale, 1999b: 148).

<sup>&</sup>lt;sup>3</sup> Intentionally searching for data that contradict the emerging pattern.

<sup>&</sup>lt;sup>4</sup> The degree to which participants' viewpoints and feelings are accurately understood.

situation. For instance, in the current study, theories about identity would be the domain to which the results would be transferable, which are reflected in the theoretical propositions (see Chapter Three). The themes identified in the participating care homes may also occur in other care homes. In order to achieve transferability, the theory should be tested in additional care homes to see whether similar themes emerge.

Transferability is achieved through purposeful sampling and thick description in order to provide sufficient data and detail to determine the applicability of findings in alternative settings. This study engaged in purposeful sampling of care homes across Greater Manchester, and generated thick descriptions of the phenomenon under study. Thus, the criteria of transferability was achieved.

# 4.6.2. Dependability vs. Reliability

Parallel to reliability, dependability is concerned with the "Minimisation of idiosyncrasies in interpretation" (Baxter, 1997: 512), or plausibility of accounts in relation to the design of the study. From a positivist perspective, if the study were repeated using the same methods in the same context and with similar participants, it would achieve similar results (Shenton, 2004). This is not the aim of many qualitative researchers, and often is not feasible, as the objectives focus on subjective experiences of a phenomenon, that by nature, may change over time (Seale, 1999b; Seale, 1999a; Shenton, 2004). Dependability and credibility are very similar, and achieving one criterion helps to achieve the other (Lincoln and Guba, 1985).

This study has addressed many of the ways to achieve dependability in qualitative research outlined in Table 4. It was not possible to use multiple researchers to achieve investigator triangulation, given the independent nature of a PhD, but discussions of themes with the supervisory team aided reflection and interpretation of findings. Nonetheless, reflection on the effectiveness of the research strategy occurred throughout the research process. Further, each step of the research process was operationalised as much as possible (Yin, 2009), particularly in relation to FA. As illustrated in the Findings chapter (see Chapter Five), verbatim accounts of what participants said were included throughout the description of findings, and member

checking ensured that interpretations of accounts were accurate (Lincoln and Guba, 1985).

# 4.6.3. Credibility vs. Internal validity

Credibility refers to the congruence between the constructed realities of the participants and those reported by the researcher (Shenton, 2004; Hammersley and Atkinson, 2007; Peräkylä, 2011). The researcher should be confident that the reported data reflects participants' own perceptions and experiences (Lincoln and Guba, 1985; Baxter and Eyles, 1997; Shenton, 2004; Peräkylä, 2011). For a researcher to consider an account to be valid is not the same as believing that account to represent the 'truth', as in positivism. Credibility was achieved in this study through prolonged engagement in the field, which establishes trust and understanding between participants and the researcher (Lincoln and Guba, 1985; Guba and Lincoln, 1989; Shenton, 2004). Iterative questioning (Shenton, 2004) and member checks help to uncover accurate interpretations of responses (Lincoln and Guba, 1985; Guba and Lincoln, 1989; Shenton, 2004). Furthermore, the triangulation of methods enables the researcher to take advantage of the strengths of each method whilst compensating for their limitations (Shenton, 2004). Finally, a thick description of the phenomenon aids credibility by conveying the context surrounding the investigated situations and phenomena (Lincoln and Guba, 1985; Baxter and Eyles, 1997; Shenton, 2004).

# 4.6.4. Confirmability vs. Objectivity

Confirmability identifies the subjectivity throughout a qualitative enquiry, as each researcher brings a unique perspective to a study. To achieve confirmability, the researcher should ensure that interpretations are rooted in the data and on participants' experiences, not the assumptions of the researcher (Baxter and Eyles, 1997; Shenton, 2004; Hammersley and Atkinson, 2007; Peräkylä, 2011). Again, triangulation and member checking can assist with this by reducing investigator bias (Baxter and Eyles, 1997; Shenton, 2004). Also, by using FA, an audit trail ensures that interpretation of the data can be traced to its source (Ritchie and Spencer, 1994). The prior sections have demonstrated how this has all been achieved in the current study. Therefore, the confirmability criteria has also been satisfied.

#### 4.6.5.Reflexivity in qualitative research

Reflexivity is an important skill in qualitative research (Finlay, 2002; Guillemin and Gillam, 2004; Brown Wilson, 2011). Reflexivity refers to the self-awareness of the researcher of how they may influence participants or the data, and helps to maintain the integrity and trustworthiness of qualitative research (Finlay, 2002; Guillemin and Gillam, 2004). In line with social constructivism and symbolic interactionism, reflexivity inherently supports the notion that there are multiple interpretations of reality, and acknowledges the social nature of self-awareness and meaning-making (Mead, 1934; Finlay, 2002). Data is not objectively collected and analysed by a purely bias-free researcher. Rather, the researcher actively co-constructs meanings and interpretations with participants (Finlay, 2002). Through reflexive practice, this on-going awareness of subjectivity can support the interpretation and analysis of qualitative data.

As discussed, this study uses semi-structured interviews and observations. Interviews are an important component of the dialectic between researcher and participant (Guba and Lincoln, 1989). Knowledge and meaning are actively co-constructed between researcher and participant (Holstein and Gubrium, 1997; 2011), while acknowledging that meanings and narratives go beyond that immediate interaction (Miller and Glasner, 2011). The addition of observations conducted longitudinally can help to further understand a phenomenon within its context, and help to explore changes over time. However, interviews and observations are never completely biasfree or neutral; they fundamentally influence the structure and content of the data collected (Holstein and Gubrium, 1997; 2011). Taking into consideration SIP, I belong to particular social categories, such as my age, gender and occupational role, which may influence how individuals interact with me during interviews and observations (Miller and Glasner, 2011). Participants may offer responses whilst monitoring who they are in relation to the researcher (Holstein and Gubrium, 1995; 2011). Residents may also selectively portray a particular identity or emphasise certain aspects of themselves. This is not only a practical concern when collecting data, but is also of interest theoretically, as certain individuals may respond to me more positively if they feel they are part of the same ingroup, or at least share similar

social identities.

It was important to maintain reflexivity throughout the research process to account for any potential biases or influences in the collection or interpretation of data. I wrote reflective notes alongside field notes of observations and after interviews, and referred to these when discussing ongoing interpretations of findings with the supervisory team. An example of reflexive practice is illustrated in Box 4.

# Box 4. Example of reflexive practice

I had entered Care Home 01 for a period of observation. Catherine, a resident, was having her hair done by a hairdresser in the dining area. I was making notes on our conversation. Below is a quote from field notes I took during this period, followed by my reflection on the interaction.

"There was a lull in the conversation and Catherine looked at my feet, and asked me about my shoes. I was wearing ballet pumps. She asked me whether I did ballet... Catherine then went on to tell me that she used to do ballet as a little girl at school, and very much enjoyed dancing when she was younger...Catherine joked that she wouldn't be much good at dancing now, unless she took her walker with her....[She went on to tell me] all the dances she had learned at school, and which were her favourite...She said it was a shame, because she really enjoyed it, but she can't really do much anymore because she's so frail...Catherine joked that I probably go dancing in all the clubs and discos, because I'm so young, and a 'slim, young girl'..."

Catherine (resident), Care Home 01, field notes

"It occurred to me that that particular interaction might not have happened had I not have been wearing those particular shoes that day. It reminded me of a similar conversation when Catherine and two other residents commented on my handbag, which provoked a whole narrative discussion about their changing style as they aged. My shoes stimulated Catherine to reminisce about learning to dance, and ultimately about her inability to engage in an activity that had meant a lot to her....I felt bad that my choice of footwear ended up making Catherine feel sad over her diminished physical ability...Would I have ever learned the importance of dance to her if I'd worn other shoes? Would an older or a male researcher have been able to stimulate that discussion from her?..."

Reflective diary

My shoes provoked a conversation from a resident that highlighted identity-relevant information about her. My choice of attire, age, and gender were all referenced in the residents' response. If I had not worn those particular shoes, it was likely that that informative conversation would not have naturally occurred. Furthermore, a researcher of a different age or gender may not have stimulated the same response from that particular participant. It was interesting to note the apparent impact of seemingly mundane choices, such as footwear, on participants' responses to me as a researcher. The spontaneous conversations that emanated from my clothing also demonstrated that participants felt comfortable talking to me and sharing their personal thoughts and memories.

It was also necessary to reflect on how my own personal experiences influenced the choice of observations and what to make field notes on. The theoretical propositions outlined in Chapter Three were partially informed by my prior experience of life in a care home to help guide the initial stages of the research, in addition to themes outlined in the literature. Prior to starting the PhD I worked as an assistant psychologist for people with learning disabilities, which involved visiting care homes to determine why certain older clients were unhappy or engaging in problematic behaviour. These observations as a psychologist may have influenced the particular events observed and noted on as a researcher. Furthermore, at the beginning of the PhD it became likely that my own grandmother would have to be admitted to a care home due to her advancing Alzheimer's disease. Conversations with my parents about what type of care home, their perceptions of the potential care homes they visited, and my grandmother's opinions on the matter may have also primed me to focus on particular aspects of care home life. However, one cannot be completely objective, particularly within qualitative research, and being aware of how these experiences informed the study helped to guard against making assumptions and being unduly biased in the data collection and analysis stages. As discussed above, the iterative nature of the study and regular meetings with the supervisory team, regular member checking, in addition to other quality-enhancing practices outlined in this section, helped to ensure that interpretations and analysis were grounded in the data, and credible representations of participants' experiences.

# Summary

This section discussed the working methods of the study, and the justification for those methods. A qualitative, longitudinal, multi-case study approach, utilising semistructured interviews and observational methods, and analysed using framework analysis, reflects the aims and methodological foundations of the study. The chosen methods of data collection and analysis, conducted iteratively, can enhance the quality of the study according to the criteria outlined in Section 4.6. The various ethical implications of the study were also addressed. Finally, the importance of reflexive practice throughout the study was explored, including how prior experience of working or engaging with care homes may have influenced the study . The next chapter presents the findings of the study, including information about each case and participants involved.

# **Chapter 5: Findings – Coping in a care home**

## 5.1. Introduction

This chapter presents the results of the analysis of the case studies and personal reflections from the data collection period across each of the three participating care homes. This chapter outlines the context of the care homes, including a brief description of the homes themselves. Next is a thematically structured account of the themes surrounding the social impact of the transition to a care home, its subsequent influence on identity, and how participating residents engaged in identity management within the care homes. Chapter Six explores the personal and individual impacts of the transition to a care home, also presented thematically. Many of the themes illustrated in the following chapters overlap and are connected to one another. These themes warranted being kept separate, rather than restructuring them to one larger theme, in order to highlight the complexities and idiosyncrasies of the concept of identity and identity management within care homes. Furthermore, the following chapters present a cross-case analysis. Each care home demonstrated very similar themes, so the presentation of a within-case analysis would have resulted in substantial repetition. Any differences between cases are discussed.

#### **5.2.** Context of the study

As discussed in Chapter Four, care homes in Greater Manchester were purposefully sampled on the basis of size and location. Three care homes agreed to participate, and characteristics of these care homes are summarised in Table 5, including the number of residents who had capacity to consent over the course of the study, who were therefore potentially eligible to participate. All three care homes were converted domestic properties. No managers of purpose-built care homes agreed to participate in the study.. Care Home 03 was introduced to confirm and compare themes, and so was included in the study at a later point in the data collection period.

Though the majority of data collection was conducted in communal areas, it is necessary to describe some residents' rooms to fully understand the physical context of the homes, particularly when discussing residents' personal possessions (in Chapter Six). All names have been changed to pseudonyms, and personal or identifiable information, such as place names, were changed. Pseudonyms were randomly allocated based on participants' gender. Some specific information relating to the care homes has been restricted to protect anonymity, including the fundingtype and a more detailed description of the layout of each care home. Information on residents' ages and length of residence were not formally collected, and was typically provided informally during interviews or observations. For the majority of participants, this information was withheld on the basis of concerns about anonymity. Details on length of residence was only discussed in relation to residents admitted during the course of the study, or when such information directly informed a participants' responses regarding their experiences of care home life.

Most of the members of care home staff who participated in the study were care assistants, bank care assistants, or the care home managers. No members of bank staff agreed to be formally interviewed, and the owners of the three care homes were unavailable to participate.

Feature	Care Home 01	Care Home 02	Care Home 03
Number of	17	37	28
residents (max.)			
Number of	8	8	7
residents with			
capacity to			
consent (approx.			
over course of data			
collection period)			
Type of care	Residential care	Residential care	Residential care
home	only	with nursing	only
Location	Low-medium	High income area	Low income area
	income area		
Buildings	Converted house	Converted house	Converted house

Table 5. Features of participating care homes

A summary of the data collected across the three care homes is illustrated in Table 6, including the number of interviews, hours of observations conducted, and the number of participants who had capacity to consent, with whom I conversed during observations, but did not formally interview. Field notes were made on general

observations as well as conversations between me and participants, as interrupting an interaction to request that it be formally recorded could have impaired their train of thought or interfered with the interaction. Furthermore, some participants did not wish to be formally interviewed, or there was insufficient time for them to be formally interviewed, but instead they agreed to have our conversation noted in field notes.

Data collection began in March 2013 and ended March 2014. A Gantt chart of the data collection timeline is presented in Appendix 24. To facilitate a more iterative data collection process I aimed for the case study data collection periods of each care home to overlap, to address any differing emerging themes in one or more of the care homes with other participants. Data collection occurred on different days of the week, and at different times of the day, including evening shifts (see Appendix 25).

	Care Home 01	Care Home 02	Care Home 03
Interviews	3 residents	4 residents	2 residents
	2 relatives	1 relatives	1 relatives
	2 staff	3 staff	0 staff
Observations	137 hours	84 hours	40 hours
Conversations	8 residents	8 residents	4 residents
during	1 relative	3 relatives	0 relatives
observations (not audio recoded)	7 staff	5 staff	4 staff

#### Table 6. Summary of data collected across care homes

#### 5.2.1. Care Home 01

Care Home 01 was a converted house, and owned by a family-run company. The building was located on a busy road in a fairly affluent area. It had two separate communal areas: a front lounge and a separate TV room. The front lounge was open plan and also served as a dining area, with lounge furniture near the window where some residents would sit and look out of the window. The heavy wooden dining

furniture was placed towards the back. Five residents had rooms downstairs. All rooms had single beds. Most residents had divan beds, but about five residents with physical difficulties had nursing style beds. There was a lift between the basement and the ground floor that only staff were permitted to use. Residents were not allowed in the basement, as the kitchen and laundry rooms were located there. The lift had a tendency to break down, so residents could not use it for safety reasons.

The second communal area was a TV room where the majority of lounge furniture was located. There were several chairs and sofas placed against the walls, with the television being the main focal point. On the ground floor was a large disabled toilet, and a room with multiple toilet stalls, and another separate disabled toilet. Residents were permitted to sit in the small, walled garden. There was plastic garden furniture on the grass, as well as chairs by the back door, where residents and staff went to smoke, sometimes together. Residents did not necessarily have to ask permission to sit in the garden, but were advised to inform a member of staff of their whereabouts, and staff could advise residents as to whether they should sit outside. For instance, if dinner was about to be served, or they felt the weather was not suitable, members of staff would suggest the resident did not go outside.

The majority of the bedrooms were on the first floor. All residents were permitted to bring their own furniture where there was space, such as wardrobes and side tables. The narrow upstairs corridor had a handful of chairs placed against a wall, which residents never used during my observations. On the first floor were two additional toilets and a small bathroom with a bath and shower fitting.

The doors to residents' rooms had a small plaque with their names on, which was hand-written in calligraphy by Tracey, the manager.

Over the course of the study, Care Home 01 received two new residents who had capacity to consent to participate in the study. April arrived around May 2013, and Julia around September 2013.

## 5.2.2. Care Home 02

This was dual registered as a nursing home and residential facility. The care home

was located in an affluent area of Greater Manchester, amongst residential properties, and bars and restaurants.

The bedrooms were spread across three floors. Most residents had divan beds, but about five residents with physical difficulties had nursing style beds. Some of the bedroom doors had residents' names on them, and others did not. For the residents with a form of dementia, there was personal information about them taped to the bedroom doors, including where they grew up and their hobbies.

On the ground floor was a large, open-plan communal area split in to three sections. The first was a seating area with chairs positioned against the walls. There was a large fish tank in the corner between some chairs. The second section was the dining area, which had multiple round dining tables. The dining chairs were wooden and heavy. The kitchen was through a door to the left of the dining room. The third section of the communal area, at the back, was another communal seating area with large windows facing the garden, with about a dozen chairs against the walls. This room had a small stereo that was rarely used during observations. Residents could access a small garden area, where residents and staff would smoke.

In the dining area was a large whiteboard, where the date and weather were usually written on for the residents. Rolled up on the ceiling was a large projector screen, and a projector secured to the ceiling. This was used for occasional movie nights and important football matches.

Off the large communal areas were two additional TV rooms. The TV rooms were small, and had room for about five residents in each room.

There was a lift to all the floors, which staff and residents could use. There was a single toilet on the ground floor for members of staff and more able residents, as it was small and did not have any railings fitted for disabled residents. There were multiple toilets and bathrooms on the ground floor with railings and other fittings for less able residents. Ten of the rooms had en suite facilities.

Though Care Home 02 received new residents over the course of the study, none had

capacity to consent or were eligible to participate in the study.

## 5.2.3. Care Home 03

This care home was located on a busy road in a lower-income area. It was a large converted house with multiple small communal areas. The main, larger communal area, had a large television secured to the wall, with a smaller TV around the corner. – often with different programmes playing on each. A movie channel was usually left playing on the larger TV. This lounge lead on to an open plan dining area at the back with several small square tables pushed together in rows, and light wooden seating around.

There was a fireplace by the large TV with ornaments covering it. One wall had a large noticeboard on it with information about days out secured to it, which staff informed me were for residents to choose activities. At the front of the building was a larger communal area with large cupboards with board games in them, which residents rarely entered.

There were a few bedrooms on the ground floor, but the majority were on the first floor. Two rooms had en suite toilets. There was a single toilet on the ground floor for staff and more-able residents to use. It did not have any fittings for use by disabled residents. Most of the residents' bedrooms had name plaques, and a small number had personal information about the resident taped to the door, including where they grew up and any hobbies.

Care home 03 did not receive any new residents over the course of study.

# 5.2.4. Overview of care home residents

The majority of residents had moved to the care homes because their physical and/or cognitive impairments meant that they were unable to live independently in their own homes or in their previous accommodation. Most residents in the present study experienced an emergency or rushed admission to the care home, often due to an injury from a fall.

Many residents reportedly experienced dementia either prior to or following the transition to a care home. The minority of residents included in the study experienced normal cognitive functioning. Care Home 01 had one resident with mental health problems, and Care Home 03 had a several residents with learning disabilities, mental health problems, and one with an acquired brain injury. The majority of the residents in Care Home 02 also had cognitive impairments, including dementia, with a range of severities.

Though there was no formal data on residents' ethnicities or cultural backgrounds, most residents across the three care homes were white. Based on discussions with participating residents, most were white British.

# 5.3. Social Identity Theory and Self-Categorisation Theory

As discussed in Chapter One, according to the Social Identity Perspective (SIP), the concept of identity can be split into two types: personal and social identity. Social Identity refers to the elements of an individual's sense of self that expressly relates to the interaction with other individuals. Those individuals can either be in the same ingroup, or an outgroup. Personal identity refers to the elements of an individual's overall sense of self-concept that is related to personal differences, such as personality traits and attitudes.

Several themes emerged from the framework analysis, and further exploration of these themes suggested that they too could be placed in to overall themes of "social" and "personal", as illustrated in Table 7. Many of these themes were related to one another. For example, the themes Social Comparison and Independence and Autonomy were related to the other themes, because independence was an important element of residents' identities, but they would also compare themselves to other residents in terms of their perceived independence.

Social impact		
<ul> <li>Social comparison</li> <li>Acceptance of being a care home resident</li> <li>Social comparison as a strategy to improve identity</li> </ul>	<ul> <li>Independence and autonomy</li> <li>Important elements of identity</li> <li>Increased dependency on staff for larger tasks</li> </ul>	<ul> <li>Frustration</li> <li>Symptomatic behaviours of dementia frustrated all participants</li> <li>Differing expectations of care</li> <li>Dementia, false memories, and tension around the truth</li> </ul>
<ul> <li>Personal impact</li> <li>Personal identity vs. Care home</li> <li>A care home is not a home</li> <li>Meaningful possessions reflect personalities and identities</li> <li>Activities</li> <li>Routines of the care home restrict identity</li> <li>Mealtimes: The importance of food for identity</li> <li>"I look a damn mess": Clothing and identity in the care home</li> <li>Social relationships: Others reflect the self</li> </ul>	<ul> <li>Ageing and changing</li> <li>The ageing process initially undermined identity</li> <li>Personhood and dementia</li> </ul>	

# Table 7. Themes and sub-themes from framework analysis

# **5.4.** Social comparison

# 5.4.1. Acceptance of being a care home resident

According to SIP, individuals can belong to more than one social group, but the salience of those multiple social identities changes depending on the context. Being a care home resident is the most salient social category for residents because of its pertinence in their everyday lives. Residents in the study accepted being labelled as a 'care home resident', but also acknowledged the stigma around such a label.

"... most people think people in care homes are, well, decrepit [laughs]. I suppose they think we're all loony...That's what I always thought...I live here now. I'm not able to live by myself, on my own. So I'm here. In a care home. I've had to accept that. I accept that now."

Catherine (resident), field notes, Care Home 01

"....She said, with a hint of disgust, 'This is me now' and she gestured to the room..."

Julia (resident), field notes, Care Home 01

"I live in a care home. I'm not as bad as this lot [gestured to other residents in the communal area that appeared to have more severe physical and cognitive impairments]. But I suppose that's who I am now...He [Louis] said 'places like this are full of people like that...'"

Louis (resident), field notes, Care Home 03

However, many residents engaged in social comparison to reduce the impact of this supposedly negative social group, and to maintain a positive sense of self.

## 5.4.2. Social comparison as a strategy to improve identity

The theme of social comparison occurred across all care homes and during the majority of observations and interviews, particularly through conversations with residents. The process of social comparison was related to most other themes and served to inform the maintenance of identity. Individuals typically engage in social comparison, whether positive or negative (Festinger, 1954; Corcoran *et al.*, 2011), but social comparison clearly played a significant part in care home residents' identity management following the transition to long-term care.

Initially proposed by Festinger (1954), social comparison refers to the judgment and evaluation of opinions and abilities of others, with the aim to accurately, yet positively, define the self. The process of social comparison was then included in Tajfel and Turner's (Tajfel and Turner, 1979) Social Identity Theory, and Self-Categorisation Theory (Tajfel, 1978; Turner, 1982; Turner *et al.*, 1987) as an important element of the social identity process. Once we have categorised ourselves

into groups, we then compare ourselves to other groups to maintain positive selfesteem. To achieve this, the group must compare favourably to another group. Other studies have identified that if an individual belongs to a negatively perceived group, it can impact their sense of well-being (Howarth, 2002; Haslam *et al.*, 2009). Individuals who belong to a negatively labelled social group are motivated to maintain a positive self-image by using ways of coping and challenging negative representations. These strategies were outlined in Chapter One, but to reiterate, they are: social mobility (physically or physiologically leave the group); social creativity (re-frame the ingroup; change dimensions of comparison; compare themselves to lower status outgroup; make intragroup comparisons); and social competition (direct competition with the outgroup) (Tajfel and Turner, 1979; Tajfel, 1981; Howarth, 2002; Reicher *et al.*, 2010; Jetten *et al.*, 2011; St. Claire and Clucas, 2012).

Through interviews and observations it became clear that residents without dementia exercised the strategy of social comparison more than any others. Residents without dementia engaged in judgement-based social comparison with residents with dementia or residents with severe physical *and* cognitive need, in order to highlight their relative perceived superiority. Comparisons were mostly based on their diminishing physical and cognitive abilities that were related to participants' perceptions of their sense of independence and successful cognitive functioning. This was typically a linear comparison between residents without dementia towards residents with dementia, mental health problems or learning disabilities. Members of staff and relatives also made comparisons between residents with and without cognitive impairments or mental health problems.

# 5.4.2.1. Sympathy as a mechanism to highlight differences

One of the ways residents, staff or relatives actuated their comparisons between other residents was via sympathy. Staff and relatives would express sympathy towards all care home residents, regardless of impairment, for the sheer fact of having to live in long-term care. Staff and relatives would state how 'awful' it must be for them to move to a care home, and leave behind their social networks and personal relationships. They understood the difficulties faced with such a significant life transition. Staff and relatives also felt sorry for residents who did not have cognitive impairments for having to 'put up with' interacting with residents who did, with whom they could not make a meaningful connection:

"....The member of staff said it was a shame for some of the residents who could hold a conversation, but had no one to talk to. She pointed out a female resident I had not spoken to before, who was sitting alone with her walker beside her. The member of staff said that other than her mobility, that resident was 'all right', but is surrounded by residents who cannot 'think properly..."

Field notes, Care home 02

"... I feel sorry for her [Catherine] because she has to listen to these [residents with dementia] going on and on, doesn't she? I do feel sorry for her [inaudible] And Alwen never shuts up..."

Susan (relative), interview, Care Home 01

All participants expressed sympathy towards care home residents who experienced severe cognitive and physical impairments, who were generally bed-bound. These residents would regularly call out, seemingly in pain, which would distress participants:

"Rachel (a resident with severe cognitive and physical impairments who died during the course of the study) could be heard shouting from her room in the background. When there was a lull in the conversation and we heard her even clearer. Barbara said that it was horrible to listen to her, but in a manner that suggested she felt sorry for Rachel and did not like hearing her in pain"

Field notes, Care Home 01

All participants without dementia made comments about how it was "a shame" for those with dementia to be experiencing confusion and other symptoms. Such expressions of sympathy were typically coupled with comments about how they would "hate to be like them". There was care home wide agreement that dementia was one of the worst experiences for an older person, and was considered to be one of the worst consequences of ageing they could imagine. Participants also acknowledged that interacting with individuals with dementia could also be distressing or frustrating:

"I feel sorry for them. They're kind of locked away in their own world..." Edna (staff), interview, Care Home 02

"I'd hate to be like that [motions towards resident with severe dementia]" Richard (resident), field notes, Care Home 03

"But it's surprising, erm, with the old people being, you know, some of them are a bit out of their mind, which is, I wouldn't say anything bad about them. But they are, and they say some terrible things to these girls [the staff] sometimes."

Mary (resident), interview, Care Home 02

"She's [Gladys] like that all the time. I feel sorry for her, but it doesn't help me....Nobody smiles. Everyone's ill [with dementia] – I feel sorry for them."

Julia (resident), interview, Care Home 01

"....even the poor souls [residents with dementia] that are in here, you know, they're so nice. You know, I just feel sorry for them..."

Meredith (resident), interview, Care Home 02

Residents without dementia, relatives and staff considered residents with dementia, particularly those with severe physical impairments as well, as a 'yard stick' of ageing. As long as you are not 'as bad' as those residents, then you were not the oldest of the old and not the subject of unwanted and dehumanising sympathy. For residents without such impairments, regular social comparison was necessary for the creation of a positive sense of identity within the care home, to reject the stigma of being a care home resident:

"One of the female residents was making a lot of noise, calling out for her mother and shouting obscenities to no one in particular. Even with the TV on quite loud, she could still be heard very clearly. The residents in the TV room with me, one by one, but independently, looked at me, rolled their eyes and tutted, then smiled. David said he's getting fed up of her making so much noise and was glad he wasn't like her. He joked that he'd rather die than end up like her. A few of the men hummed in agreement..."

Field notes, Care Home 02

"Louis asked for his lighter back from Naomi. She told him that she didn't have his lighter, but he politely said that he thinks she was the last person he lent it to...Naomi then left the room. Louis turned to me and said that she was "all right", but "gone in the head", and "mad as a box of badgers. He told me that she was good for a laugh, but you couldn't have a proper conversation with her. You couldn't have a proper conversation with anyone really. Apart from myself, and the staff..."

Field notes, Care Home 03

"You know it's bad when you end up like that..."

Louis (resident), field notes, Care Home 03

Several residents across the three care homes had mental health problems or learning disabilities, and fewer were involved in the study due to issues with obtaining consent. Therefore, the data regarding residents with mental health problems or learning disabilities was based on observations and conversations with about four residents. Nonetheless, it was useful to highlight the slight differences regarding these residents.

Residents without a mental health problem, learning disability or acquired brain injury would occasionally expressed sympathy towards those that had such conditions:

"Richard said he felt sorry for the residents with dementia and learning disabilities. He said it wasn't their fault that they were ill, and that it was a shame. He looked towards a resident with a brain injury, and tutted. He said he was a nice guy, and that it was a shame, and that living how he lived must be terrible."

Richard (resident), field notes, Care Home 03

"I don't know what's wrong with him [Marcus], but it's a bloody shame" April (Resident), field notes, Care Home 01

However, there was a level of detachment associated with these expressions of sympathy, unlike with those with dementia. When residents expressed sympathy towards those with mental health problems or learning disabilities, there was no immediate emphasis on their own abilities in comparison, or expressions of fear over having such a condition. This may be because residents without any cognitive or mental health issues perceived that a severe mental health problem or learning disability was unlikely to affect them, whereas there was a possibility they could be diagnosed with dementia in the future, or at least be associated with dementia.

# 5.4.2.2. Sympathy between marginalised groups

Social comparison did not occur as frequently with residents with mental health problems, learning disabilities, or cognitive impairments such as dementia. This finding may be a due to the comparatively smaller number of residents with mental health problems or learning disabilities observed across the care homes. Nonetheless, there were examples of reciprocal comparisons made between residents with mental health problems, learning disabilities, and those with dementia. Residents were aware that the other had cognitive or mental health issues, and would engage in similar distancing mechanisms used by residents with no such impairments:

"Marcus [who has mental health problems] said that he feels sorry for Alwen because of her dementia and the fact that she cannot remember where she is. Marcus also said that he was glad he did not have dementia. He would not like to lose his memory like Alwen."

Marcus (resident), field notes, Care Home 01

"Marcus was making a lot of noise; making music with his mouth and being loud. Alwen looked at me and rolled her eyes...Marcus was making noise again. Alwen said that she was getting fed up with his noise...She said she knew he was 'daft...not right in the head, is he?'..."

Alwen (resident), field notes, Care Home 01

"A female resident with dementia had her coat on and looked confused...A member of staff asked if she was okay, and suggested she take her coat off as she looked hot...A[nother] female resident who I knew to have dementia laughed and said 'everyone here's mad'..."

Field notes, Care Home 03

Furthermore, residents with dementia and residents with mental health problems or learning disabilities engaged in comparisons with severely cognitively and physically impaired residents. They believed themselves to be not 'as bad' as those residents, but also did not realise or acknowledge their own impairments. Some residents in this group would approach me and point out more severely impaired residents, and state that they felt sorry for them and would hate to be like them.

"...Gladys pointed at Joan, who was sitting in her chair, sleeping. She said that it was a shame for her, and that she was lovely, but that she would still not want to 'end up' like her...."

Gladys (resident), field notes, Care Home 01

"A resident with dementia walked past me. As she did, a severely impaired resident seated next to me let out a groan. The other resident looked at her, then me, and said it was a shame for her, and 'bless her'..."

Field notes, Care Home 02

All participants rarely discussed residents with severe cognitive *and* physical impairments – those who were typically bed-bound - without provocation. When I first entered the care homes and asked about what the residents were like, the staff never mentioned the severely cognitively *and* physically impaired residents, even in passing. It often seemed as though they were background characters until they did or said something that warranted attention, such as making a lot of noise:

"There were a couple of residents at the dinner tables who I had never seen before. They didn't speak to anyone and appeared to me to be very physically impaired, as they could not feed themselves, and they didn't interact with anyone. I asked a member of staff whether they were new residents...The member of staff told me that those residents had lived at the care home for some time, but that they rarely left their rooms...I found it strange that I had been to this care home for several months now, and had never seen these residents, and had never heard anyone mention them at all...Or speak to them...I did not see anyone speak to [them] all day..."

Field notes, Care Home 02

"...it occurred to me that even though Amelia often sat in the TV room, no one ever spoke about her. I never saw her speak to anyone, or anyone – apart from staff during meal times – speak to her..."

Field notes, Care Home 01

Residents with severe cognitive and physical impairments were almost never seen and rarely heard. These residents almost never formed part of the daily discourse within the home, and were only usually commented upon when they were ill and/or making noise.

## 5.4.2.3. Cognitive impairments as a source of social comparison

Maintaining cognitive faculties served as a means of comparison between residents. Residents with cognitive impairments who suffered recurring memory problems were pitied and judged because they could not recall significant information about their own lives, and often acted abnormally. Residents without dementia appeared to be concerned at the prospect of losing their mental faculties, and the consequences of this. These consequences include impairment in completing daily activities, and no longer remembering important identity-relevant information, such as significant personal memories and family members. Out of this concern, they made negative comparisons against residents with a form of cognitive impairment, and emphasised that they still retained these capacities themselves:

"He said, 'it's a shame for 'em [residents with dementia]. It's not their fault. Now I might be getting forgetful in me old age, but I still have me marbles. Well, most of them anyway'. He laughed..."

Louis (resident), field notes, Care Home 03

"I sat next to Philippa. She looked fed up and I asked if she was okay. She was looking at the row of residents sat asleep against the wall... 'Most of these have lost their minds, you know...I can still think for myself. I haven't gone yet...'

Philippa (resident), field notes, Care Home 02

".... 'I might be old and decrepit, but at least I'm not as bad as [Alwen]. I know it's awful to say, but it's true'..."

Catherine (resident), field notes, Care Home 01

"Thankful that you're not in that state, you know."

Meredith (resident), interview, Care Home 02

These comparisons could be related to the concept of personhood (Kitwood, 1997). Residents without dementia were concerned about losing their cognitive faculties to such an extent that they were no longer considered to be the 'same' person they once were. Therefore, they were motivated to make comparisons with residents with dementia in order to emphasise their own abilities, and that they were still the same person.

Cognitive impairments were also related to increased dependency in the care home, which was another source of comparison.

# 5.4.2.4. Independence and autonomy as a source of social comparison

Being independent and autonomous was a major element of many residents' identities, and emphasising their independence was a source of social comparison between residents. Anyone who was not able to maintain his or her own independence because of failing cognitive or physical impairments was considered to be inferior. Residents with no cognitive issues and no, or comparatively few, physical impairments would compare their physical independence with residents who needed more assistance with activities of daily living, sometimes criticising their high levels of dependency.

"....some of them in there, they won't even try and help themself...."

"I might be in here, but I can still look after myself. Not like them lot" Mary (resident), field notes, Care Home 02

"Some people in here, some of them, the ones who've lost their minds, <u>choose</u> not to do anything for themselves, you see. They could...I suppose some of them aren't able to...But I've never been one to do nothing..."

Louis (resident), field notes, Care Home 03

For many participants, this acknowledgement of others' cognitive impairments and severe physical disabilities, and the impact of this on their independence, served to maintain a psychological distance. As discussed in Chapter One, according to the Social Identity Perspective (SIP), individuals who are members of negatively perceived ingroups are likely to attempt to influence the perceptions of themselves to improve their self-esteem. Residents with no serious cognitive impairments engaged in social creativity strategies, to promote a more positive impression of themselves. Highlighting their differences to residents with more advanced impairments (the outgroup) enabled less impaired residents (ingroup) to feel superior. These sorts of comparisons are in line with SIP. Residents could not physically remove themselves from the care home in order to construct a more positive identity, so relied on social creativity strategies.

#### 5.5. Independence and autonomy: Important elements of identity

Most residents considered being independent and autonomous to be an important element of their identities, including being physically able to engage in daily activities and being socially autonomous enough to engage in whichever activities they chose. Their relatives confirmed this. The concept of independence was a source of social comparison and conflict, but warranted the status of being a separate theme because of its prevalence throughout the data:

"I'm independent. Very independent."

Catherine (resident), field notes, Care Home 01

"Oh I've always been independent, me...I never let anybody do anything for me...Even me mom and dad used to say how independent I was...Well I've always been like that, even as a young girl, you know. I used to be terribly independent. You know, people say 'let me do that for you', and I say, 'no, I want to do it me self." Mary (resident), interview, Care Home 02

"Oh me mum was always independent. She's always been independent." Susan (relative), field notes, Care Home 01

"...when she was at work, she was very much independent – very decisive..." Daniel (relative), interview, Care Home 01

"...being independent was very important to me. Very important." Richard (resident), field notes, Care Home 03

"I had a career for myself"

Julia (resident), interview, Care Home 01

Members of staff were often sympathetic to the impact of the transition to a care home on residents' independence, and how difficult it must have been for them to adjust.

"Well – in some cases they have everything taken away from them. You know, whether that be finances, control of finances, control of their life, control of their social life, control of their – could be – drink habits, food habits. They have everything taken away and re-evaluated. And well, it's controlled isn't it in a way?" Adam (staff), interview, Care Home 01

Residents felt that their independence and autonomy was threatened following the transition to a care home. This belief was largely based on their knowledge of stereotypes and negative representations of what it meant to live in long-term care; specifically, being dependant, frail and slow. Becoming a care home resident usually involves giving up autonomy and authority over one's own body to health care professionals, and altering individually tailored, and personally significant routines

to fit in with the institution of long-term care. After moving to the care home, residents became more aware of the constraints associated with living in such an institution.

"I've accepted this life [in the care home]. But I would like to be independent." Julia (resident), interview, Care Home 01

"I was worried I wouldn't be allowed to do what I was used to. Independence, you know."

Meredith (resident), field notes, Care Home 02

"I don't want to be one of those, those women, sitting down doing nothing. I don't do nothing. Never have done."

Louis (resident), field notes, Care Home 03

Prior to moving to Care Home 01, April felt she had maintained her independence, because paid carers followed her orders. Following the transition to the care home, April found herself unable to control the day's activities, and disliked these circumstances. She was unable to act on her perception of herself as being an independent individual, and often felt constrained and oppressed by the routine of the care home.

"...April said she was fed up with having to wait for the staff all the time...She said that she 'the girls' [hired care assistants] in her flat would get her up whenever she asked for it...April said she was fed up and wanted to go home... 'You can't even get a cup of tea when you want one'..."

Field notes, Care Home 01

Some residents said that they were motivated to remain independent in the care home. There was a sense of "use it or lose it". If residents did not exert their independence within the care homes they were in danger of losing it altogether; both physically and socially. Residents wanted to maintain as much independence and autonomy as possible out of fear of becoming too dependent on members of staff or assistive technologies. There were generally mixed feelings about whether residents could remain independent following the transition to long-term care, despite the maintenance of independence and promotion of choice being key criteria in the Care Standards (Department of Health, 2001).

"I mean I think it's very kind of them [the staff] and all that – but to me it's not helping me to get right. You see, because if they're going to do it for me, I'll never want to walk. That's why some of these people are old, you see. They can do better if they tried, but they don't try...."

Mary (resident), interview, Care Home 02

"If I don't look after myself, I'll end up like them."

Louis (resident), field notes, Care Home 03

Participants also acknowledged the disparity between the desire to remain independent and the acknowledgement that the resident required at least some form of care or assistance.

"Any kind of personal care, which I find with a lot of them, but erm, she was very resistant, erm, obviously a very proud lady – feels as though she could do it herself when she obviously couldn't manage because she has a stoma as well, so we have to do that for her."

Tracey (staff - manager), interview, Care Home 01

"It's difficult to keep some of them happy because obviously a lot of them need help...It's all well and good saying they want to remain independent, but if you can't walk, you can't walk...It is our job at the end of the day – to keep them well..."

Edna (staff), field notes, Care Home 02

Residents frequently described themselves as 'independent' when they were younger, and their relatives also described them as independent prior to the transition to a care home. Residents also tended to describe themselves as being independent following the transition to a care home. However, the specificities of this independence changed. While the importance of being independent remained the same, the activities residents performed to justify the label of being 'independent' had changed. Residents would acknowledge their decreased independence due to physical or institutional constraints, and increased reliance on members of staff for support. However, being able to engage in comparatively minor everyday tasks in the care home was seen as a victory and kept them motivated to maintain this independence. Such as when Mary refused help from staff when walking around in the care home and getting out of her chair:

"It was a walk I wanted to do. In my way I was trying to help myself, you know, because I'm like that, I'm very independent really in those kind of ways...I said no, I'm used to getting myself up."

Mary (resident), interview, Care Home 02

"Edna told me about the time that a member of staff wanted to bathe Mary when she first moved to the care home, but Mary was adamant that she could bathe herself. Edna said that Mary could be a bit feisty, as she was quite independent and wanted to stay that way."

Edna (staff), field notes, Care Home 02

"Catherine re-entered the room and helped to place the cutlery on the tables. She told me it makes her feel "useful", even though she cannot walk about much", and added "I know I'm not completely independent anymore. But it's something..."

Catherine (resident), field notes, Care Home 01

"Sandra had a small table next to the settee with a small kettle on it, some rice cakes and tea bags. I recalled that said she likes to be independent and do little tasks for herself like making her own tea..."

Field notes, Care Home 01

"I mean nobody tells you to do it... if I don't do anything, like say after tea, they'll be there for a long time and that sort of thing. Get all the things, have they finished with them? Right, put it on the tray, take it through, take the cloth off and put it on the side. It's all easy to do that – I've done it that many times I get used to it [laughs]....I figured it's better I do. Nobody always tells me to. But I think I could be doing something rather than sat here – and helping, so I do. Not all the time, but I do..."

David (resident), interview, Care Home 02

For health and safety reasons, residents were not allowed to assist staff with a great number of tasks, but residents tended to appreciate the allowances staff made to keep them busy. However, sometimes staff completed these tasks themselves because it was easier and quicker than allowing residents to do it, which would upset those residents who relied on assisting with those tasks to achieve a sense of independence. Despite this, some staff acknowledged the importance of completing such tasks to residents:

"Yeah, and we give them little things to do. Like Catherine said 'I'm fed up', and I said 'would you like to set the table?', she said 'I'd love to'. It's a big thing for her, just setting the table.... I think some of it is probably what she used to do. Memories of what she used to do. And wants to carry on doing that, you know, feeding the family."

Tracey (staff - manager), interview, Care Home 01

#### 5.5.1. Increased dependency on staff for larger tasks

Residents' sense of independence was also influenced by the perceived and actual level of dependency on assistance from staff. Part of this dependence came from residents' physical abilities, and partly from the health and safety regulations of the institution itself. Though residents endeavoured to maintain their independence in the care home, all residents depended on members of staff to some degree. Even those who were reasonably physically able still relied on staff for particular daily tasks, including food preparation and travel arrangements:

"Catherine told me that her son can pick her up and take her home for dinner or a family gathering whenever she wants, but it has to be 'okayed' by Tracey first."

Field notes, Care Home 01

Residents who were technically free to leave the care home for short periods were restricted by the availability of family members or staff members to take them out, such as if a resident wished to go to the shops. Some participants stated that they believed several residents with severe cognitive and physical impairments had not been outside in years, particularly those with no significant others to organise such an activity:

"I bet some people here have not been outside – I don't mean out in the yard – outside... Not for years and years and years .... They're stuck in all day. They're not moving themselves, you know what I mean, they're not getting out, or if it's nice – about taking them out in the yard for a bit – for a bit of fresh air and that. But it's such a hard job for the staff to take them all out like that. Then you got to bring them back in and that."

David (resident), interview, Care Home 02

Conversely, a minority of residents were able to exert their autonomy in particular ways, with certain residents travelling in to the community when they wanted to. Residents always had to gain staff approval before they left the care homes, and approval was not always given for healthy and safety reasons, so this was a slightly restricted autonomy. Nonetheless, it was surprising that in Care Home 01 a frail male resident was allowed to go to the shops to collect his pension and purchase confectionary. According to the staff, this freedom gave him much pleasure:

Kirstie (staff) then went upstairs to Conrad's (resident) room. I asked how Conrad managed to get all that money in his room. Barbara said that he goes to the bank to get it. I was surprised, because Conrad seemed to be quite fragile. Barbara said that Conrad likes to walk to the shops on his own, just to buy crisps and little snacks.

Field notes, Care Home 01

But this freedom was not afforded to other residents in Care Home 01 due to a risk of falling or getting lost. Whereas in Care Home 03, some residents were allowed to visit the local church fete without a chaperone: "Naomi (resident) told me she had just been to the shops...She had been to the local church, which had a market, or jumble sale...I asked whether she went alone. Naomi said she went with another resident...The staff allowed her to go to the church unaided..."

Field notes, Care Home 03

In Care Home 02, however, David (resident) enjoyed going to the local shops and pub, but had to take a member of staff with him when going to the pub. David was sometimes unsteady on his feet, and the addition of a member of staff was for his safety. According to David, he tried to do this every week, and there seemed to be no issues with this routine.

"I go to the corner there and have a look at the shops and everything. You know that way down there [points]. I can get the bus up and go see the village of \_\_\_\_\_. I always bang in to somebody I know."

David (resident), interview, Care Home 02

There were very few examples of other residents across the care homes being able to exert their independence in this way. Additional activities that were important to residents, and how these were achieved, are discussed further in Chapter Six. Briefly, the autonomy of most residents to choose which meaningful activities to participate in was often restricted by the routines of the care home, and physical ability of the resident. Only Sandra argued that living in the care home had *improved* her independence and sense of autonomy:

"I didn't have a very good childhood. Me mother kept leaving us... I were a baby and me dad had TB. He he was in and out of the sanatorium, you know. And me mother kept leaving us, for years... Me and me brother had to go in a home... Well I couldn't look after myself at home – I've got arthritis really bad. Cos that's why I had me bed downstairs - I couldn't walk upstairs. So that was the big advantage .....Yeah. Oh yeah. This is the happiest time of me life. By being in the home. I haven't got the worry, I haven't got nobody to come in and beat me up and get me. I mean, when I came in there, the manager then said 'nobody can come in here for you. Nobody can get you anymore.' You know...Well I've changed for the better because I'm more content. Since I've come in here I'm more content. I've got no worries, have I?..."

Sandra (resident), interview, Care Home 01

Sandra's transition experience was very different to all other residents interviewed. Sandra chose to move to a care home, over seventeen years ago, after a traumatic burglary left her feeling unsafe in her home. She was the only resident who wanted to move to a care home, where the majority of others were advised to move to longterm care, and eventually accepted this fact, or was admitted following an emergency. For Sandra, the care home was a safe environment that provided good food, and where she could 'look after herself'. She said she organised her own medications, and phoned the pharmacist and arranged for her own chiropodist to visit the care home. This was confirmed by Tracey, the care home manager. This freedom enabled Sandra to consider Care Home 01 to be her home, and for her to feel independent, despite being unable to walk very far. Perceptions of places, such as care homes, are influenced by both past and present experiences (Wiles, 2005), and for Sandra, moving to the care home meant that she could reconstruct her life in a way that was meaningful to her in the new context of the care home. Being an independent person was a significant element of her identity, which was jeopardised following the burglary and difficult life prior to the care home. Taking responsibility for her own healthcare was how she exerted her independence in the care home. Sandra also mentioned having her own kettle with her own teabags, a television, and snacks in her room, so she could watch what she wanted and have a cup of tea without relying on staff.

"She's [Sandra] quite able, knows what the tablets are, and rings the doctor herself, and orders them, gets them, if some of them are missing she'll be on the phone asking where they are. So yeah, she's not er – she'll ask for what she needs... Yeah, yeah always. You know, she doesn't use our hairdresser –she gets her own, - she doesn't use our chiropodist – gets her own, you know so yeah... Er, just to keep that little independence, I think. You know, because if she used ours it was – well you're having your hair cut Saturday at three o'clock. She might not be well enough to have it Saturday at three o'clock - so she decides when - so she'll phone somebody to come in to the home when she's ready.

Tracey (staff - manager), interview, Care Home 01

It should be noted that Sandra did require assistance from staff to help her move due to her physical disability, but there were also instances during observations where she asked staff to make her a cup of tea, despite having the facilities in her room.

"...I could hear the buzzer from upstairs. Kirstie asked 'what does Sandra want now?'. Barbara replied that she probably wanted a cup of tea making. Kirstie, frustrated, said that 'she can make her own tea. That's why she has a little kettle in her room and her own teabags. What's the point in her having it if she's going to ask us to make it all the time?..."

Kirstie and Barbara (staff), field notes, Care Home 01

So while Sandra might not have been as independent as she thought, it was her perception of her independence that was significant, and not necessarily actually how independent she was.

Sandra was the only resident identified across all three care homes who was allowed the privilege of organising his or her own medications or appointments. When questioned why Sandra was still allowed to organise so much of her own healthcare, staff seemed to suggest that it was simply because she had done so since moving to the care home while physically and mentally able, before the current manager started working there. There seemed to be an element of 'that's how it always has been', though staff emphasised that they do check that Sandra is still able to understand the relevant information about her medication, and would take over responsibility as soon as she shows signs of being unable to complete these tasks.

While independence was considered to be an important element of residents' sense of identity, there was often a difficult balance to support this while providing good quality care. Residents expressed frustration towards those who appeared to make little effort to maintain independence in the care home. Feelings of frustrations permeated many interactions across the care homes.

#### 5.6. Frustration

Though social relationships and interactions were an important element of daily life in the care home, these often resulted in tensions and frustrations between individuals. Disagreements occurred between all participants. The sympathy participants felt towards residents often developed in to frustration. The main sources of conflict were residents with a form of dementia, because of their often repetitive or disruptive behaviour. Staff and residents also regularly disagreed on the terms of their care. Staff and relatives became frustrated with one another when they disagreed on how well the residents were being cared for and what constituted good personal care. Residents felt frustrated that they were unable to exert their independence within the care home, which, as discussed, was an important element of their identities. Staff, consequently, became frustrated when they felt residents and relatives expected too much, but they also understood their frustrations whilst highlighting issues with under-staffing and limited resources.

#### 5.6.1. Symptomatic behaviours of dementia frustrated all participants

Residents with no cognitive impairments and members of staff would sometimes get frustrated with residents who had mental health problems or cognitive impairments such as dementia. These residents would sometimes exhibit unusual or repetitive behaviours. Residents with dementia would regularly forget important information about themselves and their lives, including the fact that they lived in a care home. For instance, Alwen's (Resident with Alzheimer's from Care Home 01) nearconstant vocalisation of her desire to go home and see her husband (who was deceased) would upset other residents, because she unintentionally highlighted the fact that no one else was 'going home'. Marcus (Resident with mental health issues from Care Home 01) would frequently make the noises of musical instruments with his mouth, sing and dance, and would talk at length about himself. Regina (Resident with Alzheimer's from Care Home 02) would often shout and scream very loudly, for no apparent reason, at all times of the day. Lauren (Resident with severe dementia from Care Home 03) would frequently approach everyone in the care home, no matter whether resident, staff or visitor, and ask them for a cigarette, and sternly stare at them or become aggressive until they gave her a satisfactory answer.

Though participants were aware that residents with impairments were often not aware or in control of their behaviour, these types of behaviours became draining over time. Residents and the members of staff said that they liked most of the residents, and while those with cognitive impairments were "nice" and "sweet", they could sometimes be overwhelming and frustrating:

"...Gavin [male resident with acquired brain injury] was making a lot of noise and clapping his hands, as he generally does a lot of the time anyway. Louis would occasionally tut and rolls his eyes, as I think he was interested in watching the movie... Gavin shouted particularly loudly, and Louis shouted back 'would you give it a rest?', and 'I just want some peace and quiet for once...I want to watch this bloody film'..."

Field notes, Care Home 03

"[Alwen] (resident) – sometimes I just want to get hold of her and love her, and I do feel really truly sorry for her...Sometimes I let her stay in her own little world...But then it gets to you so much..."

Catherine (resident), interview, care Home 01

"...Regina was calling out 'all my friends are dead'....Mary and I were trying to continue our conversation, but Regina's voice was sometimes too loud. Mary shouted as loud as she could – she has a very quiet voice – 'oh shut you, you silly sod!' and told me that all she hears is 'that bloody woman'..."

Field notes, Care Home 02

"Gladys was in the disabled toilets shredding toilet paper and paper towels over the floor...I popped my head round, and could see she had also urinated on the floor...Catherine became agitated and said 'I need to use that loo...She's made a mess of it and now one of the staff has to clean it up...I need to use the lavatory and she's made a terrible mess'..."

Field notes, Care Home 01

"Just the downside is the barning. When they're all barnying. Scrapping between them. There's a woman [Naomi] in there that likes to argue with everyone."

Residents often joked that they had to leave the room to "escape" the residents with dementia or mental health problem. Catherine told me that in order to escape the noise and frustrations of being around Marcus, she spent more time in her room. Even the staff were aware of the reasons behind Catherine's absence:

"Ruth told me that she tends to stay in her room. She likes her room and has plenty to keep her occupied. But she also said that some of the residents with dementia can get a bit loud, which she does not like."

Ruth (resident), field notes Care Home 02

"Kirstie mentioned to Barbara that she has not seen Catherine for 'ages'. Barbara said quietly, looking at me and smiling, that she thinks Catherine has taken to staying in her room more to escape Alwen and Marcus, because 'they can get a bit much for her, and annoy her a little bit'."

Field notes, Care Home 01

"Louis complained that the other residents often get on his nerves because they are loud or have annoying habits. But he then joked that if he didn't sit in the communal areas, he'd never see anybody."

Louis (resident), field notes, Care Home 03

As some residents had physical impairments that made moving around the care home difficult, they sometimes felt 'trapped' with residents that irritated them. For example, Julia was a newer resident in the care home who could not walk without a walking aid, and had difficulties getting out of her chair without assistance:

"She [Julia] said that all she has to look at 'tillyflop over there', gesturing to Gladys who had fallen asleep in the chair opposite, and 'that other one' [Alwen], who 'always talks about her husband coming to get her.' Julia said 'it drives you mad, because you know no one will ever come'. Julia added 'I know it's not her fault, as she's not a full shilling...but I cannot stand her.'"

Field notes, Care Home 01

Most residents chose to complain about certain individuals when they were not in the room, or out of earshot. Though there was rarely any explicit conflict between residents, there were a handful of occasions where normally placid residents would lose their temper with other residents and say so either to that resident or another person in the vicinity.

The only outwardly aggressive resident who did not have dementia was Anne from Care Home 01, and a handful of other residents across the three care homes that did not wish to be included, or could not be included in the study in any capacity because of an inability to consent or gain assent. Anne had a reputation throughout the care home, among staff and other residents, as being difficult and bad tempered. She also disliked the residents with dementia. Through conversations with staff I learned that she used to be aggressive towards other residents, but had been told by staff to stop or risk eviction. However, when Marcus (with severe mental health problems) moved to the care home, Anne became verbally aggressive towards him. Marcus' bedroom was next door to her bedroom, and he had apparently kept her up with his music. Marcus was then moved to another room, but Anne continued to be aggressive towards him whenever he began playing 'music' with his mouth or dancing in communal areas.

"The 'music people' [entertainment service visiting the care home] played jazz music for Marcus, and he started to 'play' along with his 'trumpet', and started to dance. Everyone in the room was laughing, and Catherine joked that Marcus was clearly loving all the music. Anne started to shout 'shut up' very loudly. Marcus continued to dance and 'play' music [with his mouth]. Anne then got out of her chair, walked over to Marcus with her walker and attempted to 'run him over' or hit him with the walking aid...She sat in her chair, and started to shout 'you're a cunt' repeatedly at Marcus, and very loudly. Marcus looked at me, smiled, and continued."

Field notes, Care Home 01

#### 5.6.2. Differing expectations of care

Staff and residents would become frustrated with one another over their differing expectations of care in each of the facilities. Sometimes members of staff believed that residents demanded too much staff time or attention, and did not appreciate the care needs of other residents. Residents sometimes felt that the staff could do more to improve their care, and to facilitate residents expressing their independence and autonomy within the home:

"Holly was calling out "Please Mrs" to everyone who walked passed her. The staff were rushing around trying to sort out lunch and were bringing in all the residents with mobility issues. Holly reached out and continued to call "please Mrs". Nancy walked passed her as Holly called out again, and Nancy looked at me and said, somewhat annoyed 'oooh, what's the matter <u>now</u>, [Holly]?". She walked away and rolled her eyes, sighing heavily. She looked annoyed..."

Field notes, Care Home 02

"...I entered the room and saw Barbara (staff) handing out cups of teas. She was saying to a resident 'I know, but I've only got one pair of hands and I'm doing the teas at the moment'...I offered to help hand out the teas so Barbara could sort out whatever it was the resident wanted...Barbara sighed and said 'there's always something, they just can't wait five minutes'..."

Field notes, Care Home 01

"...Francine (staff) was clearly a bit annoyed but tried to come across as mockingly annoyed... 'ooooh, Hayley. There's always bloody something isn't there? It's a bloomin' maid you're after'..."

Field notes, Care Home 03

Conflicts also emerged when members of staff felt they had 'wasted their time' or resources on a particular resident. For example, if a member of staff had made an effort with a resident, and the resident dismissed their efforts and complained:

"...April (resident) told Kirstie (staff) that she wanted potatoes at lunch...Kirstie told Barbara (staff) that April didn't want her potatoes, despite initially saying that she did want potatoes for her lunch. Barbara and Kirstie were already quite flustered because it was only the two of them serving lunch....April looked at her plate and did not look pleased with her meal. Barbara asked whether she wanted to eat it, and April replied that she 'never asked for potatoes'. Kirstie, annoyed, replied that she had asked April if she wanted potatoes, and April had said she did. Kirstie then stopped and said 'I'm not starting with you, April. If you want something else I'll get you something else, but all that's prepared for you at the moment is them potatoes, so you'll have to hold on.' Kirstie shot a 'fed up' look at Barbara and continued to serve everyone's lunches..."

Field notes, Care Home 01

Such examples made staff feel undervalued and unappreciated by the residents, creating tension and furthering the strain of an already pressurised job, which was further compounded by understaffing and limited resources:

" 'Why should I bother if she's [April] going to do that again? I don't have time to make food for her to change her mind...She said she wanted potatoes, didn't she?...It makes me look bad when she's sitting there telling everyone – saying she doesn't like the food...I shan't bother next time'...Kirstie was clearly annoyed and upset...I knew she would make an effort with April again, and was just upset. Kirstie generally makes an effort with most residents..."

Kirstie (staff), field notes with reflection, Care Home 01

In contrast, residents sometimes felt like staff were not taking them seriously, or treated their wishes as inconsequential:

"Asking. You have to ask for everything here. They decide whether you get it. Doesn't matter what you want."

Hayley (resident), field notes, Care Home 03

"I'm fed up here. It's horrible. They treat you like shit. All I asked for was a cigarette..."

Sheila (resident), field notes, Care Home 01

"...David told me that he was fed up with the staff making fun of him over his pretend girlfriends in the care home. He said the staff are always commenting on it, and wheeling Peggy in to the TV room, saying things like 'here's your girlfriend, David'. He often goes in to the TV room to get away from her because she 'talks nonsense' [due to her dementia diagnosis]. It's really annoying him because he doesn't fancy Peggy...David looked and sounded upset about the situation...He repeated that he was fed up with the staff, and that he did not fancy Peggy, and that it was no longer a joke...This was the first time I'd seen David act like this and he seemed genuinely annoyed and upset..."

David (resident), field notes, Care Home 01

Residents would also get frustrated because they felt overlooked in comparison to other residents in terms of daily care and choice of activities. Residents were generally sympathetic to how busy staff were, and did not wish to be a nuisance, but they nonetheless disapproved of how this impacted them on a daily basis:

"A male resident was complaining that he never got to watch what he wanted to watch on TV because everyone always chose ITV...He said he might as well stay in his room because he can't do what he wants..."

Field notes, Care Home 03

"....if there are twelve residents – 11 of them want to go to an art gallery, whereas 1 just wants to go to bingo, they'll probably go to the art gallery. ...Frustrated. They get frustrated. But hopefully, you know, next time they'll do something that meets that person's social needs. And, so, then the other 11 are unhappy [laughs]."

Adam (staff), interview, Care Home 01

"Catherine said she understood why the staff have to see to the residents with dementia, or those who were in their beds, before they saw to her. But she sometimes gets fed up of having to wait around, when all she wants is a drink to take her pill..." Field notes, Care Home 01

There were sometimes differences between what residents told me during interviews, and what they said or did during observations. In interviews, residents tended to emphasise the positive aspects of the care homes, but during observations they tended to make small complaints to me. For example:

"Well all the staff are good. Can't complain about the staff. I haven't got a bad word for any of them. Even the ones I don't like [Laughs]."

Louis (resident), interview, Care Home 03

"They treat you like babies in here. You can't do anything for yourself... They just about make sure you're fed and watered. But that's about it..."

Louis (resident), field notes, Care Home 03

Most explicit conflict came from residents with dementia. For example, some forgot that they had just eaten, and then complained to staff that they were not being fed, or could not recall that they lived in a care home and became confused and agitated when they could not go home:

"I could hear a male resident loudly complaining about the food. I saw as a female member of staff asked him what was wrong....His ability to communicate fully was impaired, but the member of staff worked out that he disliked something about the meal...She offered him an alternative meal. The resident aggressively declined, and shouted complaints about the lack of food...The member of staff sighed heavily and looked annoyed."

Field notes, Care Home 02

"A female resident with severe Alzheimer's...was shouting that nobody talked to her and that she hated living 'here'...Nancy said that she had chatted to the resident all morning as she was dressing her and changing the bed sheets...She said it was a lovely chat...Nancy said that it's sad, because you make an effort and they [residents with dementia] forget what you have done."

Nancy (staff), field notes, Care Home 02

"Alwen also said that she was hungry and had not eaten yet, but Barbara smiled and mouthed to me that she had had her breakfast".

Field notes, Care Home 01

Members of care staff would become frustrated with managers and owners for not supplying sufficient resources or providing more staff, which affected the care they could provide, which then led to complaints from residents and relatives. Adam from Care Home 01 overtly criticised the structure of the care home, and indicated that the financial "hierarchy" determined decision-making in the care home, which ultimately led to frustrations between stakeholders:

"... There can be conflicts...At the end of the day it is a company, and - ... - there isa hierarchy you know - it starts with the residents right here [indicates the bottom], and then it goes carers, and then it goes to the seniors, and then it goes to the managers, and then it can go to the a- but then it's not always the manager's fault, you know, you get area managers, um, who really hold the purse strings and things. Um, I do find a lot of it always comes - I do - [laughs] it sounds funny. I do find a lot of the residents do get frustrated and very angry over money....When a resident wants to go somewhere or to have a certain dinner - which is a basic need, you know - they need, you know, they all want different things. And so, you'll find yourself sometimes having to say 'we can't do that today'... They say 'I don't want soup and sandwiches' - we do offer alternatives, but we can only offer a certain amount of alternatives...the social activities are the same. It all takes money. I mean, you can only go for a spin in the wheelchair around the block before you get everso bored, so you've got to do something. Same with the holidays."

Adam (staff), interview, Care Home 01

Lack of funding and resources ultimately determined what the residents ate and did, despite acknowledgements that it was important to emphasise individuality in the care home. While it is unreasonable to cook each resident a separate meal each day or organise completely different activities for each individual, the restriction of resources meant that residents could only exert their individuality in structured, budget-friendly ways, if there were enough staff on shift to facilitate this.

These types of conflicts occurred on a daily basis, and there was at least one example during each observation across the three care homes. The frustration of staff over residents' perceived over-estimation of care, and the frustration of residents over their perception of staff efforts were typically reciprocal. During observations, it was usually easy to see both sides of the arguments, and why each participant was frustrated. For instance, Marcus (resident, Care Home 01) wanted his jogging bottoms from the laundry room, which residents were not allowed in, but members of staff stated they were too busy to find them for him, and he became upset and frustrated:

"Gabrielle (staff) told him [Marcus], sternly, that she was busy and that she would find them for him later. Marcus thanked her, but continued to repeat that it was important for him to have his jogging bottoms as they were new from Asda...[During a tea break] Kirstie (staff) said that Marcus had been 'going on about those bloody jogging bottoms all morning'. She then criticised the night staff who were in charge of washing and sorting the clothes, and how it was not difficult for them to find Marcus's jogging bottoms and give them to him, and that it was unfair for the daytime staff to pick up the slack of those on the night shift...Kirstie added that Marcus was 'doing her head in' constantly 'going on about' his jogging bottoms when she has 'thirty-odd dinners to sort out'..."

#### Field notes, Care Home 01

"I was confused as to why they [Kirstie and Mel] were sitting talking about Marcus's jogging bottoms instead of going to find them like they had promised. I understood they needed a break and a drink, but the task of going downstairs to find the jogging bottoms would surely have only taken a few minutes."

Reflective diary, Care Home 01

The whole interaction over the jogging bottoms began before observations began at 10am that morning until the late afternoon. These quotes illustrate the conflicts between the day and night staff, but also frustrations of staff over Marcus's behaviour that was perceived as unnecessary and badgering. It was frustrating to think that in the time it took them to have this disagreement, a member of staff could have found Marcus's clothes. But I also appreciated the staff's frustration with Marcus, as he would interrupt them completing other tasks for other residents, to ask them to retrieve his clothes. This example also highlights the importance Marcus placed on his new jogging bottoms, because they were new and from a shop that her

perceived to be of good quality. Marcus cared about his physical appearance, and was looking forward to wearing his new clothes, which the staff, in this instance, and failed to recognise. Clothing and identity is discussed further in Chapter Six.

Encounters such as these created some tension between participants, but there was rarely any lasting animosity between participants, even if they mentioned the disagreement to me again later on during the course of the study. Overall, residents were appreciative of the care they received, which was one of the reasons why they did not wish to complain about their care to the staff themselves. There was a sense that they felt their care was 'good enough', and they did not wish to seem ungrateful; especially as many were aware how little members of staff were paid.

Staff and relatives would also occasionally differ in their interpretations of the caring role, and the expectations of services provided within the facility. Residents' wishes sometimes contradicted the wishes of their family, which created tension with the staff as well. The latter would attempt to fulfil the wishes of the resident whilst inadvertently upsetting the family, or vice versa. There were many disagreements about what was 'best' for the resident. These disagreements were also occasionally centred around whether the relatives felt that the care home staff were acknowledging the residents' identity and individuality sufficiently within their daily care.

Relatives picked up on aspects of care that were seemingly being neglected, and would readily provide examples of disagreements they had had with staff, often specifically in relation to the expectations of the role of the latter. The relatives interviewed would accuse the care home staff of not adequately caring for the resident or not making an effort to acknowledge their individuality and identity. It was important for the relatives that staff were seen to be making an effort in even the smaller areas of daily care, such as wearing outfits the resident liked, because it made them feel that the residents were being looked after to the standard they expected, whilst acknowledging their individuality and unique identities. Relatives wanted to feel as though residents were being cared for as though they had remained in their own homes:

"Prior to the start of the interview, Richard's son, Colin, told me he had had an argument with the manager of the care home some months ago. They had apparently disagreed over an aspect of Richard's care, as Colin did not feel that the staff were looking after him properly and he was unhappy with certain members of staff. Colin admitted that he called the manager a 'fat bitch'...He said that they now joke about it and any issues were resolved."

Colin (relative), field notes, Care Home 03

"One said 'They're very good here'...The other visitor smoothed the residents' skirt and said 'though sometimes I think they just put them in whatever, sit em down wherever and let them get on with it'.... 'She's been wearing those slippers for months. We ought to get you some more, mum'..."

#### Field notes, Care Home 02

Susan, a relative associated with Care Home 01, did not have many negative things to say about the care home. This may have been due to her regular visits, and a better understanding of what the caring role entailed on a daily basis, as she had cared for her mother prior to the transition to a care home. Whereas the other relatives interviewed did not care for their relative themselves before the decision to look for long-term care. Though this interpretation is speculation and based on just four interviews with relatives.

While staff endeavoured to provide person-centred care and cater for individual needs, this was often difficult in the usual day-to-day running of the care homes, given frequent shortages of staff and resources. Staff often felt that relatives were being 'picky' or thought they 'knew best' about providing care, and that they did not appreciate the difficulties a caring job entails. Many staff were quick to point out that relatives did not always know or do what was best for the resident:

"A lot of people [relatives] don't ask these residents what do you want, what would you like. They just assume a lot. They must think that when you get to 75 or 80, you stop thinking or stop having an opinion, and they just assume they can make decisions for you, which must even add to your frustration when you live in a place like this...Well, excuse me, but it's X's choice, and in this care home we operate by residents' choice..."

Edna (staff), interview, Care Home 02

"Then the family decided – without discussing it with the lady at all – that she was going to go in a care home facility...It was traumatic for us as carers. We were very upset about it. Because we knew that's not what she wanted. And that was really going against her wishes. But the family felt that they were doing the best for her really..."

Charlotte (staff – Manager), interview, Care Home 02

According to staff, relatives would become angry if staff did not meet their expectations or perform certain tasks, whether or not the resident themselves expressed such feeling. Staff provided examples of times when they listened to the residents' wishes, but the relatives did not understand that this had occurred and became upset, such as when Edna (staff, Care Home 02) allowed a resident to have a 'duvet day'. The resident was feeling unwell, but her family demanded that Edna get her out of bed, because they felt that her still being in bed meant that she was not being cared for properly:

"Odette told me that Richard's son and her had an argument a little while ago. She laughed as she said he had called her a fat bitch...She said they're ok now...But the son was apparently upset with his dad's care and lashed out. It was apparently a misunderstanding and there wasn't an actual issue with care..."

Odette (staff - manager), field notes, Care Home 03

"I thought, poor [resident], they're talking over her as if she's not there. <u>She's</u> made the decision. She's fine...[mimicking the relative] 'Well I want her up so she can socialise'...I said 'she's happier having a day in her room today. Where's the harm in that?' They've not spoken to me since..."

Edna (staff), interview, Care Home 02

Staff tended to blame such misunderstandings on relatives who did not visit frequently enough to understand the changing needs and desires of the resident, and

the roles and limitations of care home staff. It was sometimes upsetting for staff to see residents with no visitors for long periods of time, and frustrating to then have those relatives question the quality of care they provided. Relatives appreciated the work done by the care home staff and were well-meaning in their criticisms of some elements of the care the resident received, but they felt that there was still room for improvement and particular sticking points that marred the positivity.

## 5.6.3. Dementia, false memories, and tension around the truth

Many residents with dementia would frequently express a desire to go home or believe they were to go home soon, or they would talk about their imaginary identity, or false memories (Cohen-Mansfield *et al.*, 2000). Behaviours such as these would provoke a series of tensions amongst everyone in the facilities. Staff, residents, and visitors would get frustrated with the behaviour of those with dementia, and want to remind them that they are not going home or are not who they claim to be. However, doing so would upset the residents with dementia, which in turn would result in the staff having to calm them down. For instance, when Alwen would engage in her repetitive behaviours and comments, such as that her husband was going to pick her up later to take her home, she would ask other residents whether they thought she would be allowed to go home later. She would make such comments and ask questions repeatedly during the day. Most times, Catherine would remind Alwen that she was a resident in a care home, and that she was not going home, as she lived there:

" 'This is your home now [Alwen]. You live here. I live here. This is <u>my</u> home, and your home, and everyone else's home.' Catherine then pointed to Kirstie...and myself. But they don't live here. They have their own homes to go to.'"

Field notes, Care Home 01

Staff would sometimes get annoyed with Catherine for reminding Alwen that her husband was dead and she lived in a care home. This often elicited frustrated comments from staff for Catherine to stop speaking to Alwen about the reality of her situation, because it would ups*et al*wen and get her "riled up".

"...Barbara said that she understands that [Alwen] can get a bit much for [Catherine] sometimes, but when the latter tells her that she's in a care home – and Catherine does this in a very stern, matter-of-fact way, Alwen just gets upset, 'which isn't good for anyone'...."

## Field notes, Care Home 01

Many residents with dementia, who acknowledged that they were in a care home, believed that they were only there temporarily; either because of physical ailments that they believed were now resolved, or as temporary respite for their significant others. These residents would become upset with members of staff when they asked to go home because they felt they were left in the care home against their wishes:

"Richard told me he was only meant to be there for a few weeks while his wife was in hospital, 'and now three years later, look at me. Like a caged animal'. He said that the manager was keeping him there against his will, and that he wanted to go home...".

Field notes, Care Home 03

Richard's son was aware of his father's believes about his care, and felt guilty over Richard's confusion. Relatives mentioned that they found it difficult when the resident misremembered the fact that they were not leaving the care home. It made them feel guilty for placing the resident in long-term care, despite the fact that it was done in their best interests:

"He was fine at first. But after six weeks, then it hit him. Hit him hard. He was going mad. Effing and Jeffing. He didn't like it at all. He said we've all turned against him. As a family, but... It was hard....He's got it in his mind that when his legs – when he can walk, he'll be coming home. But he doesn't realise that me mum will never ever be able to look after him. Through her illnesses... she wouldn't be able to look after him. Simply through the care that he needs. Day in Day out. He's bad on his legs. He thinks he can walk, but no. He's just really bad on his legs."

Colin (relative), interview, Care Home 03

Other residents, staff and relatives were inconsistent with whether they reminded residents with dementia of the reality of their situation. Residents with dementia most often approached staff to express their false memories or mistaken beliefs about their current living situation. Inconsistency or trepidation around this issue was present across the three care homes:

"A female resident with Alzheimer's told Nancy that she was going home after lunch...Nancy replied 'ok', and continued working...[Later], the same resident told Laura [another member of staff] that she was going home later. That member of staff told her that she was home, and offered to make her a cup of tea."

Field notes, Care Home 02

"Alwen (resident) entered the office and asked Tracey (staff) whether she could go home later, and that her husband was picking her up. Tracey told her that she can go home after dinner, and that her husband can pick her up..."

Field notes, Care Home 01

"Tracey (staff) told me that she often plays along with Alwen because it is easier than upsetting her by telling her that her husband is dead and that she is not going home. She added that telling Alwen the truth would not only upset her, but she would forget what was said and why she was upset, but she would still remain in a bad mood. Keeping Alwen in a bad mood was "not good for anyone"..."

Field notes, Care Home 01

"...A resident [with dementia] approached Odette and told her she was going home tomorrow. Odette smiled and said 'are you? That's nice, isn't it?'..."

Odette (staff - manager), field notes, Care Home 03

"...Naomi was telling a young member of staff (Kelly) about her boyfriends who she sees on the weekend [this was not true]...Kelly laughed and said 'oooh, Naomi, you little minx'. She asked whether her boyfriends buy her nice presents..."

Kelly (staff), field notes, Care Home 03

Staff who played along with residents' false memories believed that doing so was often the best option for the resident's emotional well-being and for the staff in general. In another set of observations in Care Home 01, Barbara (staff) had told me that she thinks it is cruel to lie to the residents, because:

"...they're not as bad as they think they are. They remember [being lied to]". Field notes, Care Home 01

"...A member of staff asked her [resident] why she was upset, and she said she wanted to go home and that she had to go to work in the morning...The member of staff said that she lived in the care home now, but her family were due to visit soon...They had a chat about what she did for work...I later learned that that resident hadn't worked in an office, but was a housewife...The member of staff knew this before, but didn't want to upset or confuse her..."

Field notes, Care Home 03

The staff and residents appeared to be unsure whether it was more ethically sound to reiterate reality despite the negative impact on residents' emotional well-being, or engaging in their false memories despite the confusion this could cause. Whether or not to indulge in false memories could also have an impact on the self-concept and identity of residents with dementia (Cohen-Mansfield *et al.*, 2000). The impact of dementia on self and identity has been discussed in-depth elsewhere (see (Caddell and Clare, 2010).

### 5.7. Summary

Residents without dementia felt motivated to compare themselves to residents with dementia, in order to demonstrate their perceived, relatively superior physical and cognitive abilities. The expression of sympathy towards residents with dementia, or those with mental health problems and learning disabilities, served to enhance their differences. Residents without dementia also emphasised the importance of independence to their sense of identity, and compared themselves to other residents who were more dependent. However, residents felt unable to exert their independence due to the rules and routines of the care homes (discussed further in Chapter Six), but staff felt limited with how they could achieve this. Participants'

perceptions of standards of care and reasonable expectations also created difficulties. Relatives were motivated to ensure that residents were well cared for as well has having the opportunities to exert their individuality. Though all participants acknowledged the limited resources and understaffing in the care homes, and appreciated the hardworking staff, this understanding waxed and waned and caused friction between most participants. There appeared to be disparity between making a care home 'homelike' and thus individual, whilst maintaining an environment of care for multiple other individuals.

Daily frustrations over the behaviour of residents with dementia or perceived standards of care permeated each of the three care homes. Symptomatic behaviour of residents with dementia caused tensions and occasional conflicts with other residents, which helped to fuel their comparisons. Residents and relatives also felt frustrated over their perceived inability to exert their identities and independence within the care homes. Other residents and members of staff often experienced the ethical dilemma of whether to remind residents with dementia of their reality when they forgot or misremembered important information, or to confirm their false memories. The issue was approached inconsistently by both staff and other residents, which caused further frustration, confusion, and occasional conflicts.

# **Chapter 6:** Findings – Individuality in the care home

The personal identity encompasses unique, idiosyncratic information about a person, including personality traits, memories, and physical attributes (Tajfel and Turner, 1979; Turner, 1982; Hogg and Abrams, 1988; Reicher *et al.*, 2010). Chapter Five explored the impact of life in a care home on residents' identities, the strategies they used to manage their identities, and the frustrations associated with adjustment to long-term care. In this chapter, the factors associated with personal identity will be explored, and how they are influenced by life in a care home.

### 6.1. Personal identity vs. Care home

### 6.1.1. A care home is not a home

Every resident compared the care home to his or her own home on a number of factors, including the ability to exert their personal identity through personal possessions and individualised routines. Although residents acknowledged the care home as their new homes, i.e. 'the place where they live', it was not held in the same regard as their own homes, because it did not have the same emotional importance or connections to memories and social networks as their own homes. Many residents did not feel that they could express their personalities and identities in the care home:

"I don't know what's going to happen to me. I want to go home and live in my flat. I don't want to be here. In care....I'm being looked after here. It's not like my own home. I'd much rather live in my own flat....Nobody speaks to me. If I could go back to my flat, I'd be much more at ease."

Julia (resident), interview, Care Home 01

"I'd rather be in my home again. Familiar surroundings, you know. But I suppose this is my home now..."

Meredith (resident), field notes, Care Home 02

"This is my home. Now. I suppose. Well, I live here anyway...I miss me flat. It's not quite the same here..."

Louis (resident), field notes, Care Home 03

Staff and relatives across all three care homes were aware that a care home was not an ideal substitute for the residents' own homes, and that the care homes themselves were not perfectly run. Staff and relatives sympathised with the residents, as they did not feel that they would move into a care home themselves when the time came for them to receive care:

"Yeah it's not easy moving away from your home to a place like this. Leaving everything. I wouldn't like to do it."

Field notes, Care Home 02

"...It's a shame for 'em, moving from their houses and that, and coming to a place like this'..."

Field notes, Care Home 01

"It must be hard for them...I wouldn't like to move to a place like this – a nursing home. Would you?"

Field notes, Care Home 03

"...– as much as - any home's a home, it's technically not - because it's not their home anyway. It's kind of like a test tube baby. ..with regards to – it's kind of like a home – they call it a home, but really, it wasn't created in the natural sense."

Adam (staff), interview, Care Home 01

Relatives were often involved in choosing the care homes. Some believed that the particular care home was "...the best of a bad bunch..." (Daniel, relative, Care Home 01). For most, there were elements of the care home they were displeased with, but they did not feel that there was anywhere better in the same area for their family member to move to. Relatives often cited a good atmosphere and pleasant staff when discussing how they came to choose that particular care home:

"The staff – the way they spoke to you. How many was on. Everything. You can tell an atmosphere as soon as you walk in somewhere. With patients. They have their times...Yeah they have their times between them, arguing. But, it's not often. It's a warm atmosphere."

Colin (relative), interview, Care Home 03

"...Amanda said she was impressed with the friendly staff and friendly atmosphere..."

Amanda (relative), field notes, Care Home 02

"So me and me sister came round, and er, looked at various care homes. I have to say this wasn't our first choice. But our first choice, er, which wasn't that very far from here, had a six month waiting list. Erm, and so we – but we did like the atmosphere here. Very nice and friendly, Tracey seemed friendly."

Daniel (relative), interview, Care Home 02

## 6.1.2. Meaningful possessions reflect personalities and identities

Residents had to sell or give away many personal possessions prior to the transition to a care home. People express their individual personalities through personal possessions (Gosling, 2009). Across the care homes, residents had their own rooms, most with single beds, a wardrobe and some basic shelving already provided. Most of the residents had kept some of their own furniture in their rooms, such as bedside table, as well as smaller personal possessions, such as ornaments. The managers had maintained that residents were free to bring as many possessions from their homes as they can reasonably fit in their rooms to make their rooms feel more 'homely'.

"As long as it's not too much, - if they've got a big room and they want to bring a settee, and it'll fit in, then fine. You know, erm...usually they'll bring pictures, photographs, erm, little nick nacks, ornaments, things like that. Some might bring their own easy chair in... It just makes them feel more at home, don't it, you know? It's not a nice experience, I suppose, leaving your home and coming somewhere strange, with lots of other people. So I suppose little things like that will be comforting for them. Personalise it don't they..."

Tracey (staff - manager), interview, Care Home 01

"It's something we really try and promote here. I say to the families, 'don't look at a room as if it's for you to sleep in. You've got to look at it as if it's for your parent to stay in, so please do bring in their own bedside table, their own lamp – cos they put that lamp on for the last 12 months. They're used to that lamp. Bring in all the little knick knacks. All the cherished little ornaments and bits and pieces..."

Charlotte (staff - manager), Care Home 02

"Odette said that residents can bring whatever they want in to their rooms as long as it can fit in their rooms. A lot of the rooms are quite small and already furnished, so they can't bring much. But they try to accommodate where they can..."

Odette (staff - manager), field notes, Care Home 03

Most participants agreed that it was important for them to bring items from home with them, to make their bedrooms feel more like home and stimulate happy memories. These items served as small anchors to the residents' previous relationships, social networks, and signifiers of their identities (Mountain and Bowie, 1992; Ash, 1996; Riedl *et al.*, 2013).

"It [sewing machine] reminds me of the days when I was competent." Julia (resident), interview, Care Home 01

Julia had worked as a seamstress with her husband, and her sewing machine and particular handmade garments were important to her as a reminder of an important era of her life: her 'feisty' side after she defended herself against an overly-critical sewing teacher, her beloved husband with whom she owned a tailor shop, her sense of style and feeling of independence at being able to make her own clothes how she wanted them to be made. Julia regretted not keeping the machine and some of her clothes because they were important anchors to significant memories for her. Without them, she lacked external validation of her sense of self (Cram and Paton, 1993). Julia was also concerned that she would one day forget her important memories, the anchors to her identity, and become like the residents with severe dementia who did not know who they were anymore. In losing her sewing machine and garments, Julia felt like she had started to lose herself. Other residents had similar feelings about possessions that they had to leave behind:

"Richard told me about how he used to be a photographer...Richard said that he wished he had kept his old cameras...they reminded him of some interesting times in his life. But he cannot use them anymore, especially not in the care home. 'What would I take pictures of?'."

Richard (resident), field notes, Care Home 03

# 6.1.2.1. Personal possessions act as anchors to memories and identity

Members of staff acknowledged the importance of personal possessions for residents. They not only make a resident's room feel more home-like, but can serve as anchors for identity-affirming, happy memories, or expressions of their personalities:

"She [Mary] could have what she wanted in the room. She's got her dog pictures. She's got her Eric Cantona pictures, and she's got her own bits of bedding and things like that..."

Edna (staff), interview, Care Home 02

For residents with dementia, anchors to memories were particularly important for residents with dementia. It can be very difficult for people with dementia to adjust to a new environment, given the change in layout of the building and rooms (The Dementia Services Development Centre, 2013). They are likely to have learned where everything is in their own homes over time, whereas a care home would have a completely different layout and routine. So bringing their own furniture and smaller possessions may help that resident to adjust to life in a care home because they would recognise certain possessions as their own and could remember, for example, the height of a side table or how that particular lamp turned on.

"It's that sense of belonging. When they wake up til they go to sleep they have that sense of belonging. That this is my room now, it's not just a name on a door when I look around, I know that I bought that clock at such and such a place, or I was [inaudible] that clock, and that picture there of my husband, that's a reminder of me and my husband when I was younger. It's reminding them as young people as well isn't it? That I was once a young girl, and I was once beautiful young bride..." Charlotte (staff – manager), interview, Care Home 02

It was very important for the relatives to try to keep as much of the resident's memory active as possible. Numerous photographs and items with personal significance, such as decorations from the family home or meaningful ornaments, were readily displayed in residents' rooms:

"Amanda said that it was important for her mother to have photographs of her family up on the walls in her room so that she can remember who everyone is. As she does not see her grandchildren very often, Amanda was worried that Carrie would forget what they looked like or forget their names"

Amanda (relative), field notes, Care Home 02

"...and I think that's because of the dementia, cos she can't remember much as now either. Cos in her room, I've got a massive big photo album, cos we used to get it out, you know, and she'd go through it, talking about everybody and all her relatives and everything. There's about 400 photographs in it..."

Susan (relative), interview, Care Home 01

"I got a lady – Rachel – whose family brought in photographs of everybody in the family, and it's on the wall – and it's like 'this is your auntie, this is your uncle, this is your son, this is his children' and you remind her of that all the time, you know, because she's got the dementia – 'ooooh look, there's your such a [inaudible] on the wall', and she'll look. It jogs memories as well."

Tracey (staff - manager), interview, Care Home 01

"It was part of her memory. Fun picnics – 'do you remember?'. It was like a little memory album. It was nice for her family to see all the little bits and pieces that we used to do".

Charlotte (staff - manager), interview, Care Home 02

Photographs displayed in the bedrooms sometimes helped members of staff learn about the individual residents and their lives in lieu of regular contact with relatives. When staff felt they had the time to engage with residents, most enjoyed learning about them on an individual level. It was interesting for the staff to learn about the residents' lives prior to long-term care; where they lived, what they did for a job, and any interesting stories from their pasts. Some staff learned new information about residents who they had cared for for years by conversing with them or discussing their personal possessions. Staff felt they developed a connection with resident once they learned more about them and their past, which some tried to bring in to the caring role by either organising activities they would enjoy

"...They'll [staff] come up to me and say 'have you seen this gorgeous pic of X on their wedding day? Doesn't she look beautiful? And then I will go and have a look myself".

## Charlotte (staff - manager), interview, Care Home 02

"...when you talk to them one on one, you know, in the morning when you're getting them up, or you're putting them to bed and you'll be having a chat to certain residents, and you think 'that's interesting'. You find out bits, they'll let little snippets come out – and you think, that's really interesting'. Why don't you sit and talk to the old lady next to you it, or wait til we've got five minutes to put you to bed...?"

### Edna (staff), interview, Care Home 02

A minority of participants argued that residents with severe cognitive impairment were less likely to appreciate the addition of personal possessions in their rooms, because they were too cognitively impaired to understand why they were there. They did not have the emotional connection to those possessions or the ability to recall the attached memories as they might have done prior to the onset of dementia.

"I don't think they [residents with dementia] notice their surroundings – I think they know that that's their room and they just get in bed and go to sleep. They don't – it's not as if they need possessions round them, it's just like, even if there was stuff there they wouldn't notice it...They [residents without dementia] like to have these

familiar things around them, and it's like made their home here now. Other people it's like their minds have gone that far that whatever you put in their rooms, it wouldn't register that that's from their life before they came in [Care Home 02]. They don't miss it. They never say 'oh I wish I had a few more photographs of my family here. You know what I mean? They never ask for things like that to be honest."

### Edna (staff), interview, Care Home 02

Those that expressed this opinion conceded that it was still important for residents with dementia to display or have access to meaningful possessions, even if they thought they would not be acknowledged or appreciated. No residents expressed this opinion at all, even the residents without dementia who were particularly negative about the cognitive abilities of the residents with dementia. All agreed that it was important to have personal items in their rooms in order to stimulate memories and create a positive environment for each resident.

Some residents did not have significant others or relatives who could help them bring personal items to the care home, or that the families lived too far away to bring many of the residents' personal belongings. To counter this, some members of staff made an effort to help residents acquire new possessions, particularly in Care Homes 01 and 02. Sometimes this was when residents or relatives requested an item, and other times as gifts. Residents were often unable to go shopping themselves and did not have regular contact with relatives who could purchase such items on their behalf. Typically, these items were practical or useful, such as clothes or electronics for their rooms. As residents could not "browse" shops, it would be very difficult for them to purchase more meaningful or personal items, such as particular ornaments or paraphernalia relating to their hobbies. So the only meaningful items they had access to were those in the rooms in the care homes, or those left with relatives prior to their transition. Particular members of staff purchased gifts for residents or pointed out items that they thought they would like. These gifts were often based on possessions that the resident already had or said they enjoyed, or other information they had learned about the resident such as their favourite colour. For instance, Marcus enjoyed music and it was a favourite topic of conversation for him. Tracey helped him to buy a stereo for his room to listen to his favourite CDs:

"Marcus told me that he was "so happy" and I asked why. Tracey had bought him a radio for his room so he can listen to his music. He then listed a few genres and artists who he liked to listen to...He repeated that he was "so happy". He told me that he tries to catch Tracey out by naming obscure jazz players, but she knows most of them – and laughed."

Field notes, Care Home 01

"Mary (resident) showed me a bracelet...She said a member of staff bought it for her when they went shopping a few months ago...Mary said it was red, which were 'my colours', meaning she supported Manchester United..."

Field notes, Care Home 02

"Kirstie (staff) was holding a bunch of necklaces...She bought them in for Alwen as she kept going in to other residents' rooms and stealing their jewellery, thinking it was hers...Kirstie thought that if Alwen had some of her own necklaces, she would be less inclined to go in to others' rooms...Alwen didn't have much of her own jewellery in the care home and Kirstie thinks she misses having her own things..."

Field notes, Care Home 02

The residents were very grateful for this and felt that it helped them to feel more at home in the facility by having particular items they did not or could not bring from home. The gifts also made residents feel accepted and appreciated by members of staff. Meaningful and relevant gifts meant that staff were aware of important elements of a residents' personal identity; whether it was that they enjoyed a particular hobby, aesthetic, or music etc.

Despite the policy of the care homes allowing residents to take some of their own furniture and to decorate the rooms themselves, there was actually limited scope to personalise the bedrooms. This was often due to the small size of most bedrooms, and the time and financial constraints for relatives and staff. While residents with larger rooms were able to bring more, or larger, meaningful items, others were restricted. Through the loss of meaningful possessions, and without being able to express their personalities within the care home, residents' identities may be impaired:

"We were promised when we got here that this carpet would be refitted, cos it looks a mess ... Never has been. Little things about the room -I think this room needs redecorating..."

Daniel (relative), interview, Care Home 01

"Amanda (daughter of a resident), said that the DIY man still had not put the pictures up...Amanda has been waiting for her mother's room to be decorated for months. She was promised it would be repainted...She doesn't have the time to do it herself as she lives abroad"

Amanda (relative), field notes, Care Home 02

Most of the residents' belongings had to fit in their bedrooms. Many rooms were small and already furnished, and there was limited storage space to move furniture, so residents had little room for their own things:

"It was all full cos they're all furnitured – the rooms. I just bought him [Richard, Colin's father] a telly."

Colin (relative), interview, Care Home 03

"...I just bought the clothes. It was only a tiny bedroom they gave me eventually..." Meredith (resident), interview, Care Home 02

The care homes displayed some residents' personal possessions in communal areas when they had no room for them in their bedrooms. Care Home 01 made more of an overt effort to do this than Care Home 02 and 03.

"I could see Tracey (staff) through the window bringing in April's (resident) possessions. A member of staff wheeled April in to the front lounge, while Tracey continued to bring in some items. We briefly watched Tracey through the window, when Catherine (resident) said that it is 'heart wrenching' when you have to leave everything to move here. April agreed, and looked very sad. Tracey then came in

holding a black pharaoh's bust, saying energetically how lovely it was. April looked at it fondly and forlornly, and said she loved it. Tracey then said that she knew where to put it, and I followed her to the TV room, where she placed it on the mantelpiece. She whispered to me that it might cheer April up if they made it feel more like home for her."

Field notes, Care Home 01

"There were numerous pictures of flowers and animals, with ornaments on various surfaces...Charlotte said some of them belonged to residents. She wanted to incorporate their knick knacks in the care home to make it feel more like a home..." Field notes, Care Home 02

"On the fireplace in the communal TV lounge was some ornaments and a couple of birthday cards for a resident...I asked about the ornaments, and a member of staff said some of them were residents...She thought some of them belonged to residents who had died, but wasn't quite sure about some of them..."

Field notes, Care Home 03

There was a sense that in many ways, displaying a variety of personal items from different residents in communal areas was a nice touch because it helped those residents to see the care home as their new home. But on the other hand, simply displaying ornaments and pictures did not enable a sense of 'home'. Only a small number of residents had personal items in communal areas, and in Care Home 02 in particular, many of the ornaments and pictures were from residents who had been deceased for some time, and they had just not removed those items. Nonetheless, this act enabled residents to keep particular meaningful items.

### 6.1.2.2. Rejecting personalisation

Some residents purposefully declined the opportunity to bring personal possessions in to the home. A minority of residents expressed dismay at their current situation in comparison to their lives prior to the transition, which made them feel disinclined to bring many items and memories from home. For instance, Julia, who regularly complained that she missed her flat and her sewing machine, refused to let Tracey bring her sewing machine to the home: "...there's some that don't [bring any personal belongings]. That are just the opposite. They didn't want anything from home. They don't want to be reminded of home....maybe they were ill at home and they couldn't look after themselves and they've had a few falls, and may have a few bad memories of being ill on their own, and no one there to help them. Whereas here they'll feel safe. You know so there's that side as well."

Tracey (staff - manager), interview, Care Home 01

"... 'what's the point? I can't use it anymore. Look at me.' Julia held out her hands and looked at them in disgust."

Julia (resident), field notes, Care Home 01

Louis, a resident from Care Home 03, felt the same. He told me that he did not care about bringing many personal items to the care home, and had to sell many items to help pay for his care:

"I didn't really have anything. Well I did and I didn't. I flogged it and got the money for it. To pay here...I've got a room of me own. That's the main thing. You've got your own private space."

Louis (resident), interview, Care Home 03

Julia and Louis cited their feelings of impending death and did not see the 'point' of attempting to furnish their rooms to express their identities. But Julia still wanted her handmade clothes and to dress smartly, as she had done prior to moving to the care home. So for Julia, the memories associated with many of her possessions were too painful to keep, but dressing smartly was still an important element of her self-concept. Clothing will be discussed more in Section 6.1.6. Louis was also concerned about losing his lighter, which he had owned for many years, and kept photographs of his family and items from his travels. There were no residents that had no possessions at all. Rather, the type and amount of meaningful possessions varied across participants. Louis had not actually 'flogged' all of his belongings; he had just reduced them down to a particularly small amount.

The manager in Care Home 02 discussed a resident she once knew who did not wish to move to a care home, and was not involved in the decision making process. However, though the resident was unhappy in the care home her family had chosen for her, she took the move as an opportunity to alter her personal aesthetic and decorated her room in a completely different way to her own home:

"She didn't feel she needed it all...In her room...It was a totally different room as well. You know, it's that shrinking down isn't it? All your world shrunken down to one room. So she took the things in there that she wanted. But she knew that if she wanted any of the other things, she could always find them..."

Charlotte (staff – manager), interview, Care Home 02

This was the only resident discussed who had decorated their room, but they were not a resident in any of the three care homes in the present study. That particular resident clearly had the opportunity to completely decorate her room in the facility in which she was based, whereas across the three care homes individual rooms were not decorated according to the residents' personal aesthetic, and many were in need of repair or refurbishment.

## 6.1.3. Activities

# 6.1.3.1. Different activities for different personalities: Difficult to achieve

Activities and hobbies are one of the many ways an individual can exert their individuality and sense of identity (Cohen-Mansfield *et al.*, 2010). Similar to personal possessions, they maintain links to individual's personalities, memories and previous roles. The care homes all stated that they endeavoured to keep the residents active, and tried to choose activities that the residents themselves enjoyed. However, this was difficult to achieve given the number of individuals, and thus the number of identities, in each care home. Care home staff tended to generalise residents' preferences, to make it easier to organise activities and aim to please the most amount of people:

"...It's kind of like, 'this person likes going to bingo', but it doesn't really sort of say, erm, - like so let's say someone's gay, and like to go to gay bars, and would like

to meet gay people, erm, for example. Um, or let's say someone's Caribbean and they like to go to Caribbean clubs, or Irish like to go to Irish clubs, erm and just basically – to break down the activities into– like I say you could break down these each thing into lots of aspects, couldn't you? Erm – and so I find they kind of take the headline title and that's about it."

Adam (staff), interview, Care Home 01

"People don't like the same things as I do, or I don't like the same things as they do."

Julia (resident), interview, Care Home 01

"So – like when they first come, you ask them, like what they like to do. Like, do they like reading the paper, you know,- do they like listening to music, watching TV, do they like going out for some fresh air, you know. So it's basically just asking, cos everyone's different aren't they?"

Laura (staff), interview, Care Home 02

During the data collection period I observed organised, structured activities (that was not watching television) at Care Home 01 and Care Home 02. Staff at Care Home 03 discussed conducting activities with residents, but this did not occur during the periods of observation.

The most common activity observed across the three care homes was watching television. Across the three care homes, televisions were switched on constantly throughout the day. Typically, the channels were set to ITV, apart from the one large television in Care Home 03, which was set to a film channel. I did not observe residents request to change the channel. Most residents had televisions in their own rooms, and would watch their favourite programmes on their own. There were also two smaller TV rooms in Care Home 02, with one room generally occupied by the male residents. Though the television was usually left on ITV, they did occasionally watch sporting events together, though the men rarely spoke to one another. Care Home 02 had a large projector, and occasionally held movie nights. The period of observation occurred during the World Cup, and the staff played the England

matches. While not many residents sat to watch this, most of the male residents, and Mary (resident), enjoyed watching England matches on the television.

Tracey, the manager at Care Home 01, stated that they tried to keep residents engaged in activities that were meaningful to them as individuals:

"...You get some residents that are like 'oh I used to love gardening', 'oh well let's do -', 'oh I couldn't do it anymore', you know, or they've lost interest, or they're physically not able to do it. So I have got tomato plants which are easy to grow, outside, and then I take them out 'come on let's water the plants', and then they see the tomatoes growing and they're like 'wooah'. So I have done a lot of gardening with them in the past."

Tracey (staff - manager), interview, Care Home 01

However, I did not see any evidence of this during observations, and relatives acknowledged that the staff did not conduct as many activities as they had suggested they would:

"I mean, Tracey said that they did lots of things in the afternoon, and I've never been convinced they've done as many as Tracey said they did"

Daniel (relative), interview, Care Home 01

"Well they don't do very much. When I first come up here they used to have bingo, once a week. But since she's been here [Tracey], she doesn't do it now, but we used to do. Have bingo, and erm, play bingo for prizes. And I was always winning [laughs]"

Sandra (resident), interview, Care Home 01

Care Home 02 had a few regular activities, such as a curry night, movie night, and bingo:

"Well one of our residents has asked for a curry night, and we have a lot of curry nights and stuff like that..."

"...The staff started setting up for bingo...The 'memory man' from a previous observation came in as the bingo caller...There were prizes on the table...I helped Mary (resident) to read and find the numbers...Other members of staff sat with other residents to help them with the numbers..."

Field notes, Care Home 02

During the data collection period, Care Home 02 had appointed a dedicated activities co-ordinator, apparently following complaints from residents and relatives that residents were not doing enough within the care home. A baking activity was selected because particular residents shared a common interest of baking prior to the transition to the care home:

"...Beverly [the activities co-ordinator] said that she knows a few of them liked baking when they were younger, but they have not shown much of an interest. Beverly showed me the box of cake pop mix and instruments...During this, Beverly asked whether anyone likes making cakes, and initially no one answered...None of the women spoke or seemed interested in the activity..."

Field notes, Care Home 02

However, this particular activity eventually stimulated conversations about the residents' pasts, with one resident telling stories of when she used to bake cakes for friends' weddings. One resident, Carrie, began to sing, which stimulated other residents to join in, ignoring the baking activity:

"Carrie started singing old songs and Elizabeth joined in...Beverly said she would start to prepare the toppings for the cake pops. The ladies continued to sing."

Field notes, Care Home 02

The other residents and staff all enjoyed the musical interlude and continued to sing songs, with some residents teaching one another unfamiliar lyrics. Those who were not involved in the activity appeared to enjoy listening to them sing and make jokes. Though this activity was initially organised to give the women an opportunity to bake again, its unintended consequence of stimulating reminiscence over wartime life and music was roundly positive. However, this was the only example of spontaneous reminiscence that occurred during the observations. As discussed more in Section 6.1.7, the residents rarely every conversed with one another. Staff at Care Home 02 also organised a 'memory man' to talk about local history with familiar songs in the background, aimed at residents who used to live in the area. None of the residents engaged with one another and reminiscence stopped as soon as the 'memory man' left the care home:

"...The residents engaged with the 'memory man' when he spoke about the local area and asked questions, but the residents did not talk to one another...During the conversation it was revealed that two residents had actually lived in the same area as one another, but they did not acknowledge this fact or talk to one another...Meredith and Carrie exchanged a few words on a local attraction they had both visited...As soon as the 'memory man' left, the conversation stopped and no one spoke to one another..."

Field notes, Care Home 02

Similarly, in Care Home 01, Tracey had arranged a small music group to play songs for the residents. The group had also aimed to get the residents to co-write a song with them about aspects of their lives and identities, but getting them to engage with the activity was a struggle. The staff had to corral residents in to the lounge, but some gradually started to enjoy listening to familiar songs and guessing the titles:

"...None of the residents were talking to one another about the music or the 'music people'...Catherine, Alwen, and Marcus (residents) spoke to the staff...Anne (resident) was making displeased noises and looked unhappy to be there..."

Field notes, Care Home 01

So while these activities did not initially stimulate discussion, they appeared to be positive experiences on an individual level, with most residents appreciating the activity, even if they did not readily engage with them or other residents involved. Members of staff at Care Home 03 discussed taking some residents on a barge trip, and there were leaflets about it on the pin board in the communal lounge. This was considered largely based on the assumption that residents would enjoy it, and it was an activity that would get them outside but they would also not have to walk far. However, it was not obvious that staff asked residents themselves whether this was what they wanted, and when the topic was brought up, residents did not want to go:

"Miranda (resident) said she didn't care about the barge trip and didn't want to go..."

"...I asked Hayley (resident) whether she was going to go on the barge trip, and that it looked quite good...Hayley gave me an unimpressed look and said she wasn't going..."

"...Richard (resident) said he didn't know why they're arranging a barge trip. No one wants to go and it's just 'going up and down, you don't go anywhere'...Richard said they always come up with ideas like that, but nothing ever happens..."

Field notes, Care Home 03

However, some members of staff believed that residents were likely to engage in activities even if they were initially hesitant at the idea:

"...She (staff) said 'they'll enjoy it once they're out...they just say they can't be arsed cos they get a bit lazy...'..."

Field notes, Care Home 03

"So I want to try and get them to do an Italian night, and maybe one day we'll have like a disco night or something. They do enjoy it, cos some of them will get up and dance."

Laura (staff), interview, Care Home 02

The data collection period ended before Care Home 03 was able to organise the barge trip, so I was unable to determine whether the residents who were initially hesitant at the idea had actually enjoyed the trip.

There was an assumption that most residents did not wish to engage in activities, which made organising meaningful activities very difficult. Beverly, the activity coordinator from Care Home 02, even resigned because she felt too deflated after repeated 'failed' attempts to engage residents in various activities:

"I asked Edna (staff) where Beverley (staff – activities co-ordinator) was, as I had hoped to interview her for the study...Edna said that Beverly left the care home a couple of weeks ago...She thinks it was because she 'felt a bit down' and 'deflated' because no one wanted to do the activities she'd organised...Edna said it can be a bit demoralising when you put an effort in, and 'no one's bothered'..."

Edna (staff), field notes, Care Home 02

I asked residents what activities they wanted to do, and received similar responses:

"...Catherine (resident) said she couldn't be bothered with anything beyond reading one of her books...She said no one else would get involved because they were too ill [with cognitive or physical impairments] ..."

Catherine (resident), field notes, Care Home 01

"I asked Louis (resident) whether there were any activities he wanted to do in the care home...He said he couldn't be bothered and that there was nothing to do..."

Louis (resident), field notes, Care Home 03

"She said it was a nice place, and big, but she wanted to go home and was not sure how long she would have to stay there. I asked what types of things she wanted to do if she is unhappy about the lack of activities, and she shrugged and replied that she did not know. She mentioned going for a walk, but then she said she could not be bothered to do anything else in the home. Irene (resident) said that there is never anything on the TV, even though it is always on, and she cannot be bothered with the television anyway. I asked how often the staff take them out for a walk, and she replied that she could not remember, but it was not often."

Irene (resident), field notes, Care Home 02

There were also smaller activities that care homes could not arrange because of health and safety reasons. For instance, Louis and Richard both enjoyed going to the pub with their friends, but they could not drink because of their frailties and medications. Richard relied on infrequent visits from his son to go to the pub:

"Take him [Richard, Colin's father] to the pub for a few beers. Which, that's what he misses the most... we take him to the pub down the road – for his tea and a couple of beers, which he loves, but it's hard working getting him – or taking him in the car, getting him in and out of the car. Nothing's as easy as what it seems....He used to like going to the local pub with hi friends. Just sat there having a natter and..."

Colin (relative), interview, Care Home 03

It was difficult for staff to organise activities that residents would enjoy and could actually engage in, whilst taking in to consideration their various impairments and needs, as well as health and safety concerns.

"... It's hard to think of where they can go really. You got to think about where they're going to go to the toilet and everything - so there's loads to think about before you even take them out."

Laura (staff), interview, Care Home 02

These issues, coupled with limited resources and understaffing, severely reduced the possible activities available to the residents.

# 6.1.3.2. Making new hobbies in the care home

Most resident stated that they started reading a lot more since moving to the care home, because there was not much else to entertain them. Residents who enjoyed reading, but had poor eyesight had to watch television. Conversely, Ruth from Care Home 02 took it upon herself to teach herself crocheting whilst in the care home, because she was unable to continue her other hobbies due to her arthritis. Mary (resident, Care Home 02) also started completing word searches because she enjoyed puzzles, but could no longer see the more complicated puzzles in newspapers, and did not have her dogs, which she enjoyed walking: "I never crocheted til I came here. I really enjoy it."

Ruth (resident), interview, Care Home 02

"Well I have my wordsearch. I love my wordsearch books...."

Mary, interview, Care Home 02

Ruth taught herself a new skill with no input from care home staff, and relied on the regular visits from her sons, who bought her the necessary resources. None of the three care homes enabled residents to learn new skills, despite research showing the importance of keeping resident active with established and new activities (Cohen-Mansfield *et al.*, 2010). Staff would buy Mary new word search books, as she did not have regular visitors to buy them for her. However, there were instances where Mary had completed her word search books and had no other activities to do:

"...Beverley had a look on the shelf for another word search book, but Mary had finished them...She said there was no more money left in the kitty to get any more for now, and she'd have to wait until someone went into town to get any more..."

Field notes, Care Home 02

Again, limited resources, specifically funding, determined the activities that residents completed in the care home.

### 6.1.4. Routines of the care home restrict identities

Being able to independently set an agenda for one's day within long-term care can enable a sense of mastery over one's environment, similar to the freedom of living in one's own home (Falk *et al.*, 2012). Each care home had its own, similar, routine; including set times for waking residents, for food and drink, and any activities. All the residents included in the study, with the exception of Sandra, frequently stated that they missed their own homes and routines. They were used to engaging in particular activities, or completing tasks at different times than at the care home. Some residents were used to having meals and drinks at different times, or just whenever they felt hungry, but the care homes largely did not operate in this way. Even the freedom of going against their own personal routines was a freedom many residents missed: "Don't like it here. Very strict"

### Hayley (resident), interview, Care Home 03

"Yeah it's a lot of compromise. It's a case of whilst adhering to the rules and the regulations, which they've never had to do before."

Adam (staff), interview, Care Home 01

"...Meredith told me there was a bit of compromise with the staff. 'Mostly with the little things, like a cup of tea, you know.'... 'It's a different routine from home'...She said she understood that they were understaffed and couldn't accommodate everyone...Meredith said that they sometimes make you a sandwich 'if you're peckish and they're not too busy', otherwise you have to wait..."

Meredith (resident), field notes, Care Home 02

"I miss walking me dogs, you know. Taking them out every morning for a walk. You miss it. Well I obviously miss me dogs, but you miss taking them out every morning. You get into the habit of it."

Mary (resident), interview, Care Home 02

#### 6.1.4.1. Changing daily routines to adjust for differences in identity

As discussed above, care home staff aimed to accommodate individuality in residents' rooms. This included allowing the resident to express their personal identity in how they kept their rooms and maintained personal routines:

"She's [Ruth] got bags of wool, magazines, biscuits, food. There's just stuff everywhere. It's like – but she – you can tell she's comfy like that. If the staff go up – like we've got domestic staff that go in to tidy rooms and stuff. They go in and I think they're a bit OCDC [sic] really – they like all the rooms to be the same and everything in its place. To a certain extent the staff are the same. Obviously you don't like the rooms to be dirty, but I personally don't like a cluttered area, so every time I have to physically stop myself from tidying up Ruth's table...Ruth obviously likes everything out where she can get it easy from her chair, and she's got everything she could possibly want throughout the day is an arm's reach....She is happy. She's made that how she wants it."

Edna (staff), interview, Care Home 02

"Adam (staff) remembered that Catherine (resident) needed a Smartie (chocolate) to take after her pills, and went to her room to fetch her one..."

Field notes, Care Home 01

There were multiple examples of care home staff adjusting the daily routine for particular residents, and making an effort to accommodate their wishes. Some specific members of staff across the three care homes made an effort with individual residents if they saw the opportunity to do so. For instance, when Edna allowed a resident to have a 'duvet day' simply because she 'fancied one', and the staff at Care Home 01 making Joan jam sandwiches for dinner, because this was a routine she had had since childhood:

"...If Mrs B (resident) wants to stay in bed there's no reason she can't stay in bed for a day...She's been here three months, and it's the first time she said 'can I have a lazy day in bed'...<u>She's</u> made the decision..."

Edna (staff), interview, Care Home 02

"...She's always had jam sandwiches. For supper... – jam sandwich. Right from being, young, yeah. <u>Every</u> night she'd have a jam sandwich, me mother... And that was how she was. And she had bread and jam for her supper...And she still loves her bread and jam now, yeah [laughs]. Well this is it you see, int it? It's something - ...which is nice, that they do it for her cos – all these other places they don't do things like that. You know, it's very regimented, they don't do it"

Susan (relative), interview, Care Home 01

The three care homes also made an effort to provide alternative meals, if a resident did not want something that was on the menu:

"...Kirstie (staff) asked Muhammad (resident) whether he liked his lunch. Muhammad responded, but due to his issues with speech I could not understand what was said...Kirstie told him it was okay if he didn't like it. She told Muhammad that if he didn't like his lunch, she'd ask Mel (staff) to make him something else. Kirstie asked him what he wanted, and whether he wanted Mel to heat him up the casserole from before...Muhammad nodded..."

Field notes, Care Home 01

"...A resident timidly told a member of staff that she did not want what was on offer for lunch...She asked whether she could just have a sandwich or something...The member of staff warmly said that it was ok, and asked if she was feeling alright...She said she would fetch her a sandwich in a bit..."

### Field notes, Care Home 03

However, while these examples occurred in each of the three care homes, as discussed in Chapter Five, staff would become frustrated if residents requested too much or interfered too much with the daily routine of the home. Therefore, residents really had two options when adjusting to the care home environment. On the one hand, residents could adjust to the routine and structure of the care home and amend their self-expression accordingly. On the other hand, residents could continue to fight against and criticise the rigid daily structure and find it difficult to express themselves around this. So in essence, residents could either adjust and thrive, or fight and be scorned by staff.

April and Julia (both residents in Care Home 01) moved to the care home during the course of the study, so I was able to observe how they adjusted to life in a care home over time. Both initially found it difficult to appreciate that staff could not always facilitate their wishes, and would become annoyed and upset as a result. Many participants, particularly staff, considered adjusting to the new routine to be an important factor for successfully settling in to the care home. By highlighting the importance of the daily care routine, staff felt more able to manage residents' expectations of care, to avoid disappointment and reduce complaints:

"I asked Barbara how April was settling in...Barbara said that April still hasn't got used to the routine of everything yet, so hasn't quite settled in, but she will eventually and will feel a lot happier for it..." Edna reflected this position when discussing how a particular resident settled in to the care home:

"She was used to getting what she wanted when she wanted, when she was with her son. Whereas in here, she has to wait. And she doesn't like that, you see...She's [Tamara] not got into the routine of everything <u>yet</u>. It's taking her a long time to settle in."

Edna (staff), interview, Care Home 03

There were also some contradictions between members of staff who believed they made a regular effort to accommodate individual routines, and the residents who did not feel that this occurred very often. Members of staff who I observed making more of an effort to accommodate residents' individual routines were still sometimes criticised for ignoring residents:

"Well Ruth likes to get up really early – Ruth likes to get up at like quarter to seven. So she'll like – and she likes to go to bed early as well. So – like when they first come, you ask them, like what they like to do..."

Laura (staff), interview, Care Home 02

"I like to get up early. But I have to wait for the nurse."

Ruth (resident), interview, Care Home 02

This may be due to an inconsistent approach to individual routines, for instance, where staff would sometimes get Ruth up earlier, and at other times were not able to do so. So the staff may have felt that they did this more regularly than they actually did, and Ruth felt that this does not happen as often as it should have done. Nonetheless, there were still individual staff members who made an effort to include personal routines in to daily care, even if this occurred inconsistently.

Getting used to the routine of the care home was difficult for some residents, as they had often never been in a situation where someone else dictated what they did and when. However, while the adjustment to a new set of routines was considered to be important for residents' wellbeing as they settled in to the care home, it often came across during observations that the routines were largely for the benefit of the staff. Being short-staffed was a regular occurrence across each care home, and their limited resources meant that they could not readily amend a routine to suit individual wishes on a regular basis. Across all three care homes, staff were perpetually aware of their limited resources and understaffing, which restricted their perceived ability to amend daily routines:

"With the best will in the world you want her [Tamara, resident] to settle in and get whatever she needs to make her feel comfy, but when you've got 30-odd other people, you can't spend more time with one even if they need it. You only get so many hours in the day or so many hours on your shift...If there was a clock where she [Tamara] could see it she wouldn't ask that question [when is food being served] cos she would just look at the clock and she'd know what time it was and she'd be fine...They could do with something physical on the wall to show them the routine. And I think it'd help her and others to get to know the routine. Oh it's half past 12 they're going to take us to the toilet in a minute, oh it's one o'clock, dinner will be served in a minute. Oh it's three o'clock, tea and biscuits will be coming around. They'll get to know every day this time we'll get tea and biscuits."

Edna (staff), Interview, Care Home 02

"Kirstie said she'd love to sit and chat with the residents more, and do activities with them, but if the owners came in and saw her 'doing nothing' she'd be out of the job. Even if she wasn't 'doing nothing', but was spending time with the residents. She said the owners don't really care about chatting to the residents. They only care about targets and being seen to get stuff done."

Field notes, Care Home 01

As discussed, staff often disliked it when residents tried to alter the daily routine of the care home, or if an issue arose that interfered with the daily schedule. Given the amount of work each member of staff had to accomplish in a shift, a rigid routine enabled them to schedule their day accordingly in order to maximise their efficiency. Stopping for individual concerns jeopardised this. Thus, in many cases, when staff made adjustments for an individual, they were often at a compromise:

"... Sometimes I like a lie-in like everybody. In here you can and you can't. In a certain sense you can, but if you do you miss a meal."

Louis (resident), Interview, Care Home 03

Or an acknowledgement from the resident that they may annoy the staff:

"Meredith said that staff do make changes to the daily routines sometimes, but sometimes when you ask, you can tell they would rather you hadn't asked, as they are really rather busy. She doesn't like upsetting people, so she doesn't ask very often."

Meredith (resident), field notes, Care Home 02

The insistence on meeting targets with an under-resourced workforce negatively impacted the ability of staff to accommodate individuality within the care homes, and thus encourage residents to promote a positive identity.

## 6.1.4.2. The importance of tea and biscuits

None of the care homes allowed residents to make their own hot beverages or get a snack from the kitchen themselves, unless the resident had snack foods in their rooms. All three care homes had set times to distribute a cup of tea and biscuits, but only Care Home 03 amended the daily routine of tea and biscuits for individual residents. In Care Home 01 and 02, if a resident wanted a cup of tea at a different time, they were usually told to wait until it was 'tea' time.

"A female resident asked Gabrielle (staff) for a cup of tea. It was around 2pm. Gabrielle said that she had to wait until 3pm to get her cup of tea, and added that 'it's not long now, luvvy', and left the room...

Field notes, Care Home 01

"A male resident I hadn't seen before was shouting out that he wanted a drink, and that he wanted a cup of tea. A member of staff told him he had to wait until it was time for a cup of tea, as they were about to start serving lunch."

Field notes, Care Home 02

Care Home 01 had readymade squash on a table in the TV room for residents to serve themselves a cold drink during the day. There were no such provisions in the other two care homes, and residents always had to ask for a beverage. Staff at Care Home 03 would generally make a resident another cup of tea when he or she asked for one. A member of staff would also occasionally ask residents if they wanted a drink without being prompted to do so. In addition, staff in Care Homes 01 and 02 usually said to take only two biscuits, whereas staff in Care Home 03 allowed residents to take more if they wanted. If a resident had any diet-related health problems, the staff across the care homes made sure to remind the resident to be careful with what they were eating.

"Hayley asked Victor (staff) for a cup of tea...I was surprised when he politely replied 'yeah sure, do you want a sugar in this one?'...I expected restrictions like in the other two care homes."

Field notes and reflections, Care Home 03

There was a difference in *how* residents in Care Homes 01, 02, and 03 asked for beverages: Care Home 01 and 02 residents tended to ask as though the staff were doing them a big favour, whereas residents in Care Home 03 tended to ask as though they had a right to a cup of tea, and the request was not abnormal. Though this is a seemingly minor or mundane observation, it is another illustration of how the care homes facilitated residents exerting some autonomy and control over their individual needs. In their own homes, residents could make themselves a beverage or snack whenever they wanted.

In one observation, Julia, who at the time had only been in Care Home 01 for about a week, asked for a coffee rather than tea, as she disliked tea:

"...I told Julia that is was time for a cup of tea and she seemed distressed, and said that she didn't want tea as she didn't like it. She wanted coffee...I told a member of staff that Julia didn't want a cup of tea, but instead wanted coffee...Kirstie was making the other cups of tea and seemed flustered, and rolled her eyes, asking why Julia has to be bloody different. She then said ok and told me to ask Julia how she liked her coffee..."

## Field notes, Care Home 01

The staff at Care Home 01 learned that Julia disliked tea, and on subsequent observations, reminded one another of Julia's preference when it came time to making the beverages. This minor change in routine frustrated the staff, but they did endeavour to remember Julia's preference.

The more task-centred approach in Care Homes 01 and 02, and the restriction of certain liquids and sugary snacks may be to encourage a healthier diet. Additionally, many residents with dementia would forget they had eaten and want to take more snacks, and then were not as hungry when it came to mealtimes. So in some respects, the more rigid approach to snack distribution was understandable. Nonetheless, this small example stuck out as a minor freedom allowed to the residents. Residents in Care Home 03 exercised their autonomy by deciding that they wanted a drink, asked a member of staff to assist in this need, and their need was then usually acted upon. Being able to have a hot drink when you wanted one was also linked to the perception of independence, and residents would lament that they "can't even make a cup of tea when [they] want[ed] one" (April, field notes, Care Home 01).

## 6.1.5. Mealtimes: The importance of food for identity

The daily menus at each of the three care homes were composed of predominantly traditional British food, for example, roast chicken and vegetables, sausage and mashed potato, and fish and chips. The menus included at least two options each day, and staff Care Homes 01 and 02 made an effort to check which residents wanted. Though there was no formally collected self-reported information on residents' ethnicities for this study, informal conversations with participants illustrated multiple ethnicities across the care homes, though the predominant ethnicity was White British. Each of the care homes had at least one resident of

South Asian descent. For residents who were, for example, vegetarian, either by choice or for religious/cultural reasons, this appeared to be respected in the meal plans. However, when it was not a 'requirement', but a culturally/ethnically specific type of cuisine, it was not likely to be included on a menu, i.e. a South Asian resident could be vegetarian, and they would receive a vegetarian version of British-style food. They would not likely receive a vegetarian meal that was culturally relevant to them.

Care Home 02 had two residents of South Asian origin, but did not have the option of traditional South Asian cuisine within the care home. There was an occasional "curry night", but this occurred rarely and was deemed a poor substitute for the food they ate every day at home. The male resident in particular kept strong links to the South Asian community, with visitors from the community, not just relatives, who would also sometimes bring him traditional South Asian food.

"Edna (staff) told me that Farhan's (resident) family, and people from the community, sometimes brought him food from home, because he cannot get the same food in the care home..."

### Field notes, Care Home 02

Another resident, Tamara, was of Eastern European descent, and could be heard calling out for traditional food during mealtimes. During my observations in Care Home 02, these residents did not receive any meal that reflected their cultural or social identities. Regularly meeting individual desires at mealtimes, including culturally-specific cuisine, can be time consuming and costly, as not every individual resident can have a specific meal made for them every day. There are also nutritional and health concerns; just because a resident wants a rich curry or pierogis, does not mean a care home should always accommodate this. However, there was a definite feeling that more of an effort could have been made to embrace individuality whilst taking these issues in to consideration.

Most resident enjoyed the food across the care homes, with many stating that it was one of their favourite things about living at the facility. However, I was not able to interview the residents of South Asian descent, or those from other cultural backgrounds, as those residents happened to have severe cognitive impairments and issues understanding English, which made it difficult to obtain consent and conduct an interview. This will be discussed more in Chapter Seven.

**6.1.6. "I look a damn mess": Clothing and identity in the care home** Physical appearance is another way people can express their personalities, particularly through clothing (Twigg, 2013;Twigg and Buse, 2013;Buse and Twigg, 2014;Buse and Twigg, 2015a), and also serve as anchors to memories (Twigg, 2010;Twigg and Buse, 2013). Residents tended to lose or have to give away clothes prior to the transition to a care home. Some residents did not have much of a say in which items were packed for them, because of their emergency admission to the care home. Susan's (Care Home 01, relative) son had to hurriedly pack for Joan's emergency admission, and a lodger in Julia's former flat packed her possessions for her while she was in hospital. Some residents said they had to 'make do' with what they had; often stating that they had nicer clothes at home but did not know where they were. In the instances where a resident had no clothes or too few clothes (such as with unexpected emergency admissions), care home staff would purchase clothes on the resident's behalf, or give them clothes of another resident.

Julia placed great importance on her appearance, and often talked about her homemade, tailored clothes, and sense of style. When she first moved to the care home, she had to wear clothes bought for her by staff, which were ill-fitting. This had a big impact on her self-perception:

"I want to look presentable...I did put makeup on and I did like to look glamorous..."

Julia (resident), interview, Care Home 01

"Look at me. Just look at me. I'm a damn mess...Who'd want me now?... Julia commented on the clothes the other ladies in the room were wearing, and how dull and lifeless they were. She said that she knows she is a care home resident, but she doesn't want to look like a care home resident... 'It's like the uniform of the dammed.'..."

She likened her clothes to a uniform of the residents with dementia, which is reminiscent of Jenkins and Price (1996), who stated that the neglect of appearance is considered to be an early sign of dementia, particularly for those, like Julia, who were previously smartly presented. As discussed in Section 5.4, Julia did not want to be associated with residents with dementia out of concern that others would consider her to be as dependent and "useless" as she considered them to be. The transition to the care home impacted Julia's ability to present herself how she wished, thus confirming her identity as a stylish woman. Her changed appearance also threatened to influence others' perceptions of her to a "dishevelled" resident with dementia, particularly as she had no visitors to confirm her identity as a stylish woman:

"....Although what do I care now? Who will see me like this? My Roger [husband] is gone. No one comes to see me here...What does it matter?"

Julia (resident), field notes, Care Home 01

Other residents, predominantly women, were vocal about the relevance of clothing to their self-expression, and the importance of appearing neat and tidy. However, so few residents across the three care homes went shopping. If they needed new clothes, they had to rely on family members, who, as discussed, rarely visited; or for members of staff to purchase items on their behalf. When residents needed to purchase new items, these were only ever functional and basic, and never purchased for pleasure. Staff would buy new underwear, tops, trousers or skirts, with money typically provided by relatives, though sometimes from residents themselves. These were generally as cheap as possible, which affected the quality and style of their choices. Part of the importance of clothing and other possessions is the act of making it or purchasing in oneself, or investing oneself in an object (Belk, 1988).

Most residents, with the exception of Meredith and David (both residents, Care Home 02), acknowledged that they made less of an effort with their appearance than they once did, either due to their age, or because they did not see the point in making an effort in a care home:

"...she [Catherine] always used to like wearing a lot of make-up, and always having her hair done. But she said she cannot wear as much make up any more because of her wrinkles, and she does not like how make up looks on older women when it settles in to the wrinkles..."

Catherine (resident), field notes, Care Home 01

"I was rather glamorous once...Now look at me...What's the point in making an effort in a place like this?..."

Julia (resident), field notes, Care Home 01

Nonetheless, some female residents still tried to maintain their appearance by having their hair done regularly, or wearing a matching outfit. Each of the care homes hired a hairdresser to come in either weekly or fortnightly, though not all residents had their hair done. Catherine (resident, Care Home 01) had her hair cut and styled by the hairdresser at least fortnightly, and would express displeasure when she thought her hair looked messy. Meredith (resident, Care Home 02), also had her hair styled regularly:

"I do try to make an effort..."

Meredith (resident), interview, Care Home 02

Others also tried to go shopping, if they were allowed out of the facility, or requested others purchase certain clothes for them. This allowed the residents some control over their appearance and self-expression.

"...Naomi said she was looking forward to going to the church and buying new clothes..."

Naomi (resident), field notes, Care Home 03

David (resident, Care Home 02) enjoyed occasionally going shopping with a relative and buying new clothes. He liked looking "smart" and also tried to have his hair trimmed regularly. He joked that it was so he could attract "the girls". Meredith (Care Home 02) always made an effort with her appearance on daily basis. Her hair was usually neatly styled, her clothes generally well-matched and stylish, and she often wore jewellery and carried a handbag. Being well-dressed often elicited comments from other people in the care home. The fact that Meredith was "well put together" (Mary, resident, Care Home 02) was considered to be an anomalous event in a care home.

"...I asked whether Meredith always dresses that way. The two members of staff said "oh yeah all the time" in agreement, and added 'She's dead glamorous our Meredith. Not like a lot of 'em you see in here'."

Field notes, Care Home 02

"She [Meredith] said, 'well you've got to make a bit of an effort sometimes, don't you? And laughed...'

Field notes, Care Home 02

Meredith's style elicited some negative comments from other residents:

"Meredith entered the room and was smartly dressed and was carrying her handbag...Elizabeth pulled a face and whispered 'oh, here she comes'...Carrie comes?'...Elizabeth asked 'who? Here who said. mockingly, *miss* glamourpuss...Miss superior'...Carrie laughed and said 'oh, her'. Elizabeth caught my eye and said 'you can do very well for yourself in here if you've got the money... [Later] I asked a member of staff about Elizabeth's comments about Meredith. She told me some of the women get jealous because Meredith is 'more well-off', and can afford to buy nice new clothes when she goes shopping with her children...She added that a lot of them can't get the clothes they want because they don't have the money, and even if they did they can't go out to get them..."

Field notes, Care Home 02

It appeared that being well-dressed mattered to other residents, but being unable to go out and purchase their desired clothes limited their ability to achieve this.

Issues surrounding clothing were more complicated for residents with severe cognitive and/or physical impairments. Relatives, and sometimes staff, typically knew whether the resident was a "skirt person" or a "trouser person", and their usual style of dress. For instance, Susan (relative, Care Home 01) and Amanda (relative, Care Home 02) both knew that their mothers had always preferred their tops to match their skirt or trousers, and made efforts to remind staff of this.

"Susan said that her mother always liked to wear a matching skirt and top, and that she tried to make sure the staff remembered to put her in matching clothes...She said she wouldn't have put her mother in the outfit she was wearing now...Susan said that she probably wants her mother in matching clothes for her own benefit, as Joan dementia was so severe that she was not aware of what she was wearing...But Susan knew that if her mother saw how she was dressed now, she would be mortified."

Susan (relative), field notes, Care Home 01

Understanding the clothing preferences of a resident is an indicator for good personcentred care (Brooker, 2007), but unless relatives visited regularly to remind staff how to dress the particular resident, and purchased relevant clothes, staff would regress to dressing the resident in a manner that was easier for them to deal with. Residents who were known to soil themselves were dressed in loose-fitting, easily washable clothes:

"Tracey and Kirstie (both staff) discussed buying Alwen some more skirts to wear, as she was starting to soil herself more regularly...It would be easier to change her if she was wearing a skirt..."

Field notes, Care Home 01

Some members of staff made more of an effort maintain residents' preferences and style.

"I noticed that most of the women in the care home were wearing trousers. Even those that were regularly incontinent ...I asked a member of staff about the residents' clothing...Joanna [staff], said that it's 'a bit of a faff' getting them in and out of trousers, 'but it's what they prefer'...She called over to one female resident 'and you look dead smart, don't you Amelie!'..."

Field notes, Care Home 03

"...Alwen had soiled herself...Barbara (staff) sighed and told me she'd only just changed her about an hour ago, and put clean trousers on her...Barbara joked that getting the trousers off Alwen was a difficult task, but then added 'but she likes wearing them. She doesn't like those jogging bottoms or anything, so I like to put her in her trousers. It's how she's comfy'..."

Field notes, Care Home 01

Staff also sometimes mixed up residents' clothes when doing laundry. During observations in Care Home 01, another resident was wearing one of Catherine's jumpers. Though Catherine "didn't mind" that the resident was wearing her jumper, she was also determined to have it returned because it was something she had owned for a long time and was one of her favourites. Amanda (relative, Care Home 02) saw another resident with dementia wearing her mother's glasses; she felt as though that individual were wearing "part of me mum". Amanda believed the other resident to have wondered in to her mother's room and taken the glasses, or just picked them up. The unintentional 'thieves' were wearing symbols of other residents' personalities and memories, which was distressing for the resident and their relatives.

"Amanda joked that it was a bit weird seeing her mother go from a fashion buyer who had travelled the world and had always been extremely stylish, to wearing other people's clothes... 'I mean, just look at what she's wearing now'..."

Amanda (relative), field notes, Care Home 02

Clothing can serve to express and shape identity, and for some residents, losing control over their clothing served a direct blow to their perception of identity management in the care home.

#### 6.1.7. Social relationships: Others reflect the self

Relationships and social interactions are necessary for the formation of identity (Billington *et al.*, 1998). Very few of the residents across the three care home established relationships with one another, and rarely conversed with one another. Although many residents were local to the area prior to their admission to a care home, residents hardly ever engaged in conversations about their similar backgrounds. Members of staff or visitors provoked discussions about the area, and residents generally tended to enjoy reminiscing about the area when they were younger. It was unclear why residents did not engage in these conversations unprovoked, as most clearly enjoyed such discussions.

Despite some similarities, one of the main reasons for this distance between residents was because they had comparatively few other things in common with one another. Residents with no cognitive impairment often cited their differences in cognitive ability as a significant difference. Therefore, residents who were more cognitively able did not feel as though they could hold a meaningful conversation with the less able residents, and thus wanted to keep their distance, as they did not believe the relationship to be a reciprocal one:

# "Well...you couldn't make a conversation with none of them" Sandra (resident), interview, Care Home 01 Sandra

"You can't converse with people here, you know. They're not a full shilling....Nobody speaks to you, you know...Do you die for lack of conversation?" Julia (resident), interview, Care Home 01

"you can't really talk to them. They don't remember who they are, let alone who you are [laughs]..."

Louis (resident), field notes, Care Home 02

Edna (staff) suggested that residents might not want to make meaningful relationships with other residents so they do not have to cope with the grief if the latter died:

"...,maybe they think 'well there's no point talking to you, cos you might not be here in two months' [laughs]"

Edna (staff), interview, Care Home 02

Despite the fact that residents rarely interacted with one another, residents without cognitive impairments valued the availability of other residents who were similar in ability to them. It was almost like a comfort to them that other non-cognitively impaired residents were there, even if they did not engage with them.

"April told me that she was glad people like Catherine lived in the care home, because she doesn't think she would have coped as well if she was not there. April told me that Catherine was her best friend in the care home, and she is grateful she it there."

April (resident), field notes, Care Home 01

"Oh aye, I got a good friend here. He's a good friend, a good mate. We get on well together"

Louis (resident), interview, Care Home 03

"Oh yeah there's a couple you can have a conversation with, but that's about it." Mary (resident), field notes, Care Home 02

"You can have a chat with some of them. The more 'with it' ones, you know what I mean?"

Meredith (resident), field notes, Care Home 02

Residents across the three care homes rarely received visitors. This has two consequences in terms of identity: first, residents had limited opportunities to confirm aspects of their identities with individuals from relevant social groups. Second, staff were unable to learn identity-relevant information about residents, and thus could not incorporate this knowledge in to daily care. From a Social Identity Perspective, without regular social interaction with members of a relevant social group, the resident may find it difficult to confirm their social identities, and aspects of their personal identities. For instance, if a resident considers being a mother to be an important aspect of their identity, yet has no contact with her children, it can be difficult to confirm this aspect of her sense of self.

Staff often relied on information from relatives and significant others to form an idea of a particular resident, in order to tailor care to their preferences and personalities. This was particularly important for residents with severe cognitive impairments, who could not provide this information themselves. However, with few visitors, many members of staff did not know important aspects of residents' biographies and personalities to provide such care:

"I: Do you know much about Elsie from before she moved here?

*T*: No, no, no. I think they're a bit private. A private family. Don't tell us much about her background, what she done before, anything like that."

Tracey (staff - manager), interview, Care Home 01

"...I asked a member of staff about how many visitors the residents get...She said most don't get any...I asked whether she knew much about the residents...She said 'not really', other than what is on the care plan, or similar paperwork...She added that the residents [with dementia] sometimes tell her little stories about when they were younger while she is doing care... 'The families usually tell you bits about them, and they do when they come in, but if they don't come in for ages you don't learn anything about them as people'..."

Field notes, Care Home 02

"I hadn't seen any visitors to the care home apart from Colin. I asked some members of staff whether the residents get many visitors, and they all said no. One said it was a shame...The other said they often live far away or have their own families to look after...Both agreed that there are some residents they do not know much about, aside from what the resident themselves tells them...One joked that sometimes they don't know if what the resident says is true, because they sometimes get 'mixed up'..."

Field notes, Care Home 03

"A female resident who had severe cognitive impairments was calling out that all her family were dead...Nancy tutted and quietly said to me that it wasn't that they were all dead. They just didn't visit her anymore..."

Field notes, Care Home 02

For most residents, a lack of visitors was often due to family living away from the area, or working long hours. Across the three care homes, only Susan visited her mother on a weekly basis until she died, Ruth's two sons visited her every day. A male resident received visits from his family and members of the local Muslim community, though the latter were irregular; this resident was not eligible to participate in the study, and his relatives did not wish to take part. Nonetheless, these residents were notable disconfirming cases:

"Me sons come everyday – Yeah, and they never miss."

Ruth (resident), interview, Care Home 02

"She's [Ruth] got family that come to see her every single day. But she still prefers to do her own thing in her own room, apart from meal times, when she comes out." Edna (staff), interview, Care Home 02

Not maintaining connection with their friends and families can have a negative impact for residents with and without dementia. For the latter there is the obvious concern that residents' memories will fade and they will lose important connections. But for all the residents, diminishing ties with important social networks could affect how residents view such social networks in relation to their self-concept.

### 6.2. Ageing and changing

Ageing is associated with negative stereotypes and, particularly by participants in this study, was considered to be a negative experience. Being a member of a negatively stigmatised group can have an adverse impact a person's well-being (Haslam *et al.*, 2009), so individuals are motivated to either change their group memberships where possible, or amend the interpretation of that social group. Before being admitted to long-term care, the ageing process and the consequences of ageing made the residents feel less adequate, and question their previously established sense

of self. However, the transition to a care home further undermined their sense of self, and residents felt less able to adjust to the environment to support their identities.

### 6.2.1. The ageing process initially undermined identity

Residents and relatives acknowledged that the ageing process impacted residents' abilities to perform meaningful activities prior to the transition to a care home.

"Before I was ill I used to like baking – making scones and that". Ruth (resident), interview, Care Home 02

"I can't do what I did. I'll never operate the sewing machine again. It's just the fact that it's there. And it's my past."

Julia (resident), interview, Care Home 01

"Ageing is a terrible thing"

Hayley (resident), interview, Care Home 03

The residents amended their expectations in light of their decreased physical abilities. They took control over their personal environments to make the necessary changes in order to continue to exert their identities, for example, not going upstairs because they could not use the stairs any longer, or hiring outside help:

"...Catherine said that she stopped using her bedroom upstairs because it was too difficult 'navigating the stairs' on a daily basis. So she put a bed in another room down stairs and used that. She said it was a little cramped with all the furniture, but she 'could get around'..."

Catherine (resident), field notes, Care Home 01

"...She [Meredith] said she had to move the coffee table out of her living room because she was worried about falling again. She had to move a lot of the smaller pieces of furniture out of the way to she felt safer moving around her home..."

Meredith (resident), field notes, Care Home 02

"I set fire to the kitchen, didn't I? [Later said he had forgotten something on the hob, or was not paying attention]...So I didn't cook much after that...Though not long after that I came here..."

Louis (resident), field notes, Care Home 03

Residents also made changes to their hobbies or other activities in light of their disabilities. They either changed their hobbies slightly to accommodate for their altered abilities, or gained new hobbies altogether. For instance, Ruth took up crocheting because her arthritis made it too difficult to hold knitting needles or do cross-stitching. Other residents had to change their hobbies because of the social consequences of ageing. Important social networks started to dwindle when family members left for work or started their own families, and when the residents' friends started to die:

"And then they go to this club a couple of times of the week dancing...So she did that until she was about – eighty-odd, you know. Til she was about eighty five...And then cos – unfortunately for me mother, everybody started to die [laughs], cos you know, she was still [inaudible], cos a lot of people die in their eighties, you know what I mean? So she was the last one left, in a sense like that. So...unfortunately that's what happened. She – you know, her social life – you know, wasn't as good then, because of that. Because everybody started dying. You know, one after the other kind of thing...But then she couldn't dance after cos she got arthritis in her knees, so she liked watching."

Susan (relative), interview, Care Home 01

"...some feel like they're left out and stuff, but it's hard to communicate with them when they can't heard and they can't see very well – so it's very hard to communicate with them as well, and get them involved with things....They can't really get involved in stuff if they can't like use their hands or something like that, it is hard."

Laura (staff), interview, Care Home 02

"I don't know whether they're embarrassed...Or they know that they couldn't physically hold scissors or hold a pen or - in front of their peers. Or whether that

particular activity that the co-ordinator got [Edna pulls a face] that's childish, I'm not doing that – Because they never really express their opinions"

Edna (staff), interview, Care Home 02

"... He said he used to go out drinking almost every night, playing cards with his friends. Louis said that he missed going to the pub for a drink with his friends... He said that there was 'no point', because he can't handle his drink like he used to, and that most of his friends were now dead....He said he used to be able to drink anyone under the table, but now after half a pint he feels dizzy and can't handle any more ..."

### Louis (resident), field notes, Care Home 03

The ageing process initiated the changes to identity, but the transition to a care home further undermined residents' self-concept. As discussed more in Chapter Five, residents further amended their perception of independence and autonomy in light of the restrictions of the care home environment. Being physically able to perform certain tasks, such as setting the tables for meals, helped residents to retain an important element of their personal identities. Therefore, while the physical and emotional impact of ageing initially influenced how residents perceived themselves, particularly in terms of their independence and autonomy, the transition to a care home further impacted how residents were able to exert this element of their identities.

#### 6.2.2. Personhood and dementia

Most residents, staff and relatives believed that severe cognitive decline resulted in an individual becoming a different 'person'. Participants did not consider residents with dementia to be the same person they were before the onset of the disease, with fundamental changes to their personalities, and what made them 'them'. This notion is related to the notion of 'personhood' addressed in Kitwood (Kitwood and Bredin, 1992;Kitwood, 1997) and Erikson (1968). The concept of a lost personhood as a result of cognitive impairments was a means for social comparison, but also highlighted the changes in residents as an individual. There is a widespread perception of people with severe dementia having lost an element of themselves, and not being the same individual they were before they became ill (Kitwood, 1997). This belief was upheld by the residents' own members of family, as well as other residents and members of staff who remembered the resident before experiencing signs of dementia.

"... 'She used to have a proper job. Apparently very impressive managerial role. And she had her own car. Now she can't even remember where she is, or that her husband's dead'..."

Catherine (resident), field notes, Care Home 01

"...that lady disappeared – the lady in there is not really me mum. There's not much of her that I recognise about her now."

Daniel (relative), interview, Care home 1

".... you wouldn't think it was the same woman as she has senile dementia very bad, she got it that bad she can't even talk. She was 90, she's 92 now. She had a lovely day – she was dancing! Couldn't believe it. That it's the same woman. She was dancing with her daughter..."

Sandra (resident), interview, Care Home 01

The negative effects of dementia on a resident's memory were thus considered to erode the uniqueness of that person as an individual. Without those specific memories or personality traits, that resident was no longer considered to be the same. Dementia affected relationships with family members, and drove a wedge between previously close relatives. It upset the relatives of those with dementia that the individual would sometimes forget who they were, or forget important information about their lives.

"...I asked Amanda (relative) why Carrie (resident) tells everyone that she lives in Spain and hasn't seen her in years. Amanda sighed heavily and said that she used to live in Spain, and that her mother has even visited her many times, but she has stayed in the UK for the last few months. Amanda laughed and said that she feels terrible that her mother has been telling everyone she doesn't see her. It makes her feel like a bad daughter..."

Field notes, Care Home 02

"...Susan said it upsets her when her mother cannot remember her brothers or Susan's children...It makes her feel disinclined to bring them to the care home..." Field notes, Care Home 01

"It's crazy. It's like a split personality. It's – it is – It's crazy. It's scary in a way, but – cos I've never seen it before. Like with other people. Like my daughter. She says, like, 'what's up with granddad?' It's hard to explain really, isn't it? In a way."

Colin (relative), interview, Care Home 03

Individuals with dementia are also prone to unusual behaviour, such as wandering or repetitive actions (Alzheimer's Society, 2014a). These uncharacteristic behaviours compounded the belief that the resident was changing, and 'getting worse', and they were not held in the same esteem as they were before their behaviour started changing.

"Well the things that changed are things that er, - as I say she would never...er, do anything to draw attention to herself, and yet the...er, when she was at er [independent residential facility], er, they rang us up and said she had been seen in the doorway with no clothes on, shouting at people...she was very very private, you know, and in her early days she wasn't – she wouldn't wear anything sort of low cut or short. She certainly wouldn't – very prim and proper..."

Daniel (relative), interview, Care Home 01

"Susan told me that her mother had started swearing since being in the care home, words like "oh streuth", which she never said whilst Susan was growing up. She said that if her or her siblings ever said those words they'd get a telling off, and that she doesn't think she had ever heard her mother swear before...Susan said it was strange how her mother was so against using those words when she was younger, but does not seem to care now..."

Susan (relative), field notes, Care Home 01

#### 6.3. Summary

Residents readily compared the care home facility with their own homes based on multiple related factors. Though they were able to display personal possessions, and in theory, were allowed to redecorate their individual rooms, this minor freedom was a poor substitute for their own identity-reflecting aesthetic of their homes. For many residents and their relatives, maintaining their sense of personal style through clothing was an additional avenue for them to exert their personal identities and feel like themselves. However, the transition process often meant that personal items and clothing had to be left behind or was lost. For some residents, the routines of the care homes also impacted how they dressed, with looser fitting skirts being preferred by staff to trousers, which upset those residents for whom their sense of style remained important to their self-expression.

Small changes to the daily routine was also important to enable residents to feel more 'at home' and to express the autonomy and independence that was so important to their sense of personal identity. However, given the predominantly rigid routine of each care home, residents were often left feeling as though their individual needs were not being catered for. Newly admitted residents in particular had to quickly adapt to the routine of the care home or risk being labelled as 'difficult' by members of staff if they expected an individualised type of care. Some members of staff made a conscious effort to adapt to individual needs, which was appreciated by residents and family members, but was still largely considered wanting. Even relatively small amendments to the daily routine, such as allowing residents and encourage a sense of control of the environment.

The minority of residents had the opportunity to leave the care home, even for a short period of time. This was both symptomatic of the very few, and irregular, visitors that residents received who could engage with them and take them outside, and limited resources within the care home to support residents to maintain connections outside the care homes. Most residents tended to feel that they could not engage other residents in conversation because of their cognitive impairments or perceived differences. Few visitors, few connections with other residents within the

care homes, and limited opportunities to engage with members of staff meant that many residents experienced dramatically diminished social networks. Consequently, those residents could not engage with important social relationships that were relevant to their identities.

The ageing process also had a negative effect on residents' sense of self and their ability to exert their independence. Residents were aware that they had become increasingly frail or required assistance following a fall or accident, and consequently changed and adjusted particular aspects of their lives, such as their physical environment or the hobbies they engaged in. However, the transition to a care home further undermined this, and many felt that their independence and autonomy was reduced even more due to the rigidity and risk-averse nature of the care home. Linking back to Chapter Five, re-assessing their perception of independence and autonomous actions in light of the care home environment helped to confirm this important element of their personalities. They were able to physically accomplish tasks within the care home that other residents could not. This reassessment also served as a source of comparison against residents with dementia who were also comparatively more physically impaired. The acknowledgement that were not like other, more impaired residents was important for their established sense of self. This also led residents, relatives and members of staff to acknowledge that they did not consider residents with dementia to be the 'same' individuals they once were, suggesting a loss of personhood.

### **Chapter 7: Discussion and conclusions**

#### 7.1. Overview of the thesis

This thesis is based on a gap in the literature on how older people maintain their unique identities following the transition to long-term care. The theoretical background of the study was presented in Chapters One and Three. The Social Identity Perspective (SIP) guided data analysis. There are multiple theories relating to 'identity' or 'self', and some of these are primarily designed for older people. While these theories have their merits, the SIP offers a broader approach to identity that incorporates individual and group-based processes, whilst highlighting the importance of context-bound social interactions for the development and maintenance of identity. Though SIP has been criticised for its largely cognitive, positivist approach, it does highlight the importance of interactions with others within a particular social context for identity management.

A systematically conducted thematic review of the literature on identity in care homes was presented in Chapter Two. The studies identified in the review explored the factors involved in promoting a positive environment for care home residents, including the reminiscence of meaningful memories and promotion of identityrelevant roles. Definitions of 'identity' varied across studies, or were not explicated. The review uncovered two UK-based research studies that explored the concept of identity in care homes, and included residents' perspectives. Of these two, Tester et al. (2004) did not aim to explore identity, which resulted in a small amount of identity-related information. Authors also only collected data over 24 hours, whereas Surr (2006) collected data over 6-24 months on the preservation of self in residential homes. The longitudinal nature of Surr's (2006) study and use of unstructured biographical interviews was likely to create in-depth data. However, Surr (2006) only included residents with dementia who had recently moved to the facility, which restricts the findings to a very specific sub-group of residents. Furthermore, Surr (2006) did not use observational methods. Few studies also included the perspectives of residents, relatives *and* care home staff. None of the studies included in the review used Social Identity Theory or Self-Categorisation Theory (Tajfel and Turner, 1979; Turner *et al.*, 1987) to explore the construction of residents' identities within the care

homes. The SIP offers a unique perspective on the concept of identity and how it is managed within a care home. SIT has been used in a small amount of research based in care homes (Haslam *et al.*, 2009; Knight *et al.*, 2010), and other research in health and social care (Jetten *et al.*, 2012). The review demonstrates a gap in the literature that more UK-based research is needed that explores the concept of identity in a care home over a period of time, using SIP.

SIP and literature on care homes and identity were used to develop the aforementioned theoretical propositions, which guided data collection and analysis. To reiterate, these propositions were:

- Personal and social identities are re-negotiated within the context of the care home in light of new social relationships and interactions.
- Maintaining links with previous social networks (e.g. relatives and friends) and habits (e.g. daily routines, personal décor) is important to maintain a sense of self.
- The care home environment has the potential to accommodate a multitude of identities with adequate support from individuals and appropriate resources.

Chapter Three presented the methodology adopted for the study, and Chapter Four the methods used. The present PhD was an exploratory study in to the issues surrounding identity for residents in a care home over a period of time. Semistructured interviews and observational methods sought to uncover and understand themes surrounding identity within the care home, and how residents managed their identities in this environment. Findings could help to illustrate where care home care needed improving, and what staff were doing well, to promote a positive identity amongst its residents, and thus improve well-being. Chapter Four also contains an explanation of the process of data analysis and addresses the issues of ethics and reflexivity.

The findings of the study were presented in Chapters Five and Six, structured thematically. Chapter Five primarily focused on social comparison, which was the main strategy residents used in order to promote a positive sense of self within the care home. The importance of independence and autonomy for identity were also addressed, as well as issues surrounding social interaction and frustration. Chapter Six describes the impact of the ageing process on residents' perceptions of themselves, and how the transition to a care home further influenced their personal identities. The influence of the structure and routines of the care homes on residents' abilities to exert their personal identities is also described. The longitudinal nature of the study also enabled the exploration of how newer residents adjusted to life in a care home, and any changes in their perception of the impact on their sense of self.

### 7.2. Main findings

This study has demonstrated that:

- Residents without dementia tended to engage in social comparison with residents with dementia, in order to promote a comparatively positive self-concept.
- Remaining independent and autonomous were significant elements of residents' personal identities, but the routines of the care homes severely impeded this. However, there were some meaningful examples of care home staff altering the daily routines to accommodate individuality and personal identities.
- While the ageing process appears to have an initially negative impact on residents' sense of self, it was the transition to, and subsequent life in a care home that appeared to have the most detrimental effects.
- All three care homes demonstrated a poor capacity to identify and implement regular, meaningful activities for residents. This consequently made residents feel as though they could not be themselves and conduct activities that were relevant to their identities.
- Relationships between residents, relatives and staff were tinged with frustration over differing expectations of care.

#### 7.3. Discussion of findings

In this chapter I briefly review the thesis and discuss the findings within the context of existing research on identity, and related issues, for older people residing in care homes. The process of identity management within the care home is discussed first, with reference to SIP and relevant research. Next, the impact of the organisation of the care homes on residents' abilities to express their personalities and identities is also discussed. The strengths and limitations of the study are then addressed. Finally, the contribution of the thesis to the current literature is presented, followed by recommendations for practice and further research.

The transition to a care home involves a series of losses (NCHR&D, 2006; Bridges, 2007), which can influence a residents' sense of identity. In this chapter, the predominant themes identified in Chapters Five and Six are discussed in the context of the literature. Rather than addressing each theme separately, as in the Findings chapters, themes will be discussed in relation to one another. This will illustrate the relationships between the major themes, and what this means for residents' sense of identity.

#### 7.4. Identity management within the care home

"...the deepest, the ultimate dependency is on one's own mortal body – the ultimate limit of autonomy..." (Bauman, 1992: 36)

Being independent was an important element of residents' personalities and identities. Prior to the transition to a care home, residents considered themselves to be very independent, which was echoed by their relatives. This was primarily based on the older person's strong personality and their occupations, or roles within the family. In their previous accommodations, whether their own homes or assisted living, residents were able to act more autonomously and cater for their needs when and how they wanted. The transition to a care home negatively impacted residents' independence and jeopardised their perception of this element of their personal identity. Residents tried to remain independent following the transition to a care home, but their perceptions of what counted as being independent changed with age and life in a care home.

Older people are generally afraid of nursing home admission and the loss of independence (Quine and Morrell, 2007). Residents inevitably sacrifice some of their autonomy and independence when moving to long-term care in order to receive 24 hour assistance. Nonetheless, having control is an essential part of living in a care home (Cohen-Mansfield *et al.*, 1995), but is still a contested issue. The care home

literature states the importance of facilitating independence and autonomy within a facility, as well as the relationship between loss of autonomy and risk of poor mental health (Boyle, 2005). However, the findings of the present study confirmed that institutional practices served to impede residents' control, particularly control over their bodies (Gilleard and Higgs, 2010).

Residents had little autonomy over routines, and repeatedly having to request assistance for comparatively minor daily activities, such as getting a cup of tea, undermined their sense of independence and autonomy. Care home staff were the facilitators of independence of autonomous action within the care setting; residents could not perform certain actions (e.g. organising meals, going outside of the facility, conducting activities that require resources) without staff assistance. The present study demonstrated that residents perceived the care home to restrict their ability to execute their decisions independently. The restriction of autonomy has been linked with poor mental health in residents (Boyle, 2004; 2005). While the present study did not include measures of mental health, participants' responses suggested that they were frustrated over their lack of decision-making within the home due to rigid routines, and over their inability to enact on, or not being allowed to enact on, their decisions, due to the regulations of the care home.

Encouraging more control within a care home setting has been shown to improve residents' self-reported well-being (Knight *et al.*, 2010; Haslam *et al.*, 2014). However, residents in the present study experienced an 'emotional limbo' (Falk *et al.*, 2012) or conflict between the awareness of their increased dependency and need for assistance, and the autonomous, independent individual they considered themselves to be. Staff across the three care homes also experienced difficulties balancing the treatment of residents as independent individuals, and treating them like dependent, ill people; highlighted elsewhere in the literature (Golander, 1995; Wiersma and Dupuis, 2010). As the findings suggest, it was difficult to maintain a balance between autonomy and dignity - between encouraging independence while providing adequate care. There were examples across the three care homes of staff enabling residents' decisional autonomy (e.g. the 'duvet day'); even if risk-averse regulations could not afford executional autonomy. Ultimately, in the majority of cases, residents were encouraged to live by the rules and adhere to the routines. The

longitudinal nature of the study demonstrated that newly admitted residents in particular found this aspect of adjustment difficult, which stimulated frustration and conflict between residents and members of staff.

The fact that other people, whether family or healthcare workers, were informing residents that they could no longer function unaided, severely undermined their perception of themselves as strong and independent. According to SIP, there is an assumption that an individuals' sense of self grows from interpersonal interactions and the perceptions of others. An individual's self-concept is based on their understanding of how others perceive them. If others perceive the older person to be frail and incapable for caring for his or herself, then this will evidently impact how that older person sees himself or herself. To use Cooley's (1922) metaphor of the looking glass, the residents were being faced with a reflection of themselves that they were not used to; a reflection of a frail, impaired older person who needed to accept their increased level of dependency.

Losing a valued identity, particularly through a major transition such as moving home or losing a job, can have negative consequences for a person's well-being and adjustment (Iyer *et al.*, 2008), particularly if a person's identity network prior to a transition is inconsistent with the new identity (Iyer *et al.*, 2009; Jetten and Pachana, 2012). A person is likely to resist identifying with a new social group if they do not surrender their old identity (Ellemers, 2003), or if there is no opportunity to represent their established identity within the new context (Haslam *et al.*, 2003). In the present study, though most residents accepted themselves as care home residents, they were unwilling to relinquish their perception of themselves as independent. Such a resignation would render them as similar to the negatively perceived group of residents with dementia and/or severe physical impairment. In light of the restrictions of the care home, most residents felt frustrated and unable to actuate this important element of their self-concept. Therefore, in order to reconcile their established sense of self within the new context of the care home, residents tended to reassess their definition of independence, discussed further below.

#### 7.4.1. Re-assessing independence and autonomy

Ageing can impact a person's identity (Billington *et al.*, 1998). In the present study, the physical impact of ageing initially influenced residents' perceived independence, but the transition to a care home further undermined this element of their identities. For most residents, ageing led to an increase in frailty and/or cognitive impairments, and reduced opportunities to engage in usual, meaningful everyday activities. Residents altered their environments or amended their aspirations to accommodate for their impairments, while feeling that they had retained much of their independence. Moving furniture to reduce the risk of a fall, and watching dancing instead of going dancing reflected these changes. Other research has shown that older people adjust their aspirations according to their 'objective chances' in order to accept the consequences of ageing (Higgs and Jones, 2009; Welsh *et al.*, 2012).

To counter any negative self-perceptions of ageing and increased dependency following the transition to a care home, residents' perceptions of what accounted for 'independent' changed. This served to reconcile their established identities within a new context that further impinged their expression of independence and autonomy. Residents' new perception of independence and autonomy was largely based on physical capabilities. Most residents included in this study were determined to demonstrate a comparatively higher level of independency than was expected of them, particularly to set themselves apart from other residents in the care home who were more severely impaired and heavily dependent on healthcare support. Mary's (resident, Care Home 02) insistence on using the stairs unaided was a clear demonstrated of her determination to reinforce the independent element of her personal identity.

Residents attempted to maintain their physical independence within the home by completing small tasks, such as setting the tables for mealtimes. According to Cooney (2012), one of the four crucial categories for 'finding a home' in a care home was remaining active and working. Other studies have identified the importance of engaging in small tasks and feeling 'useful' for residents' sense of control (Kellett, 1999). Having a meaningful occupation is also important for a good quality of life (Ball *et al.*, 2000) and a sense of pride (Falk *et al.*, 2012). Findings in the present study echoed other studies that suggest that taking part in a variety of

everyday activities, including housework and recreational activities, provided meaning and supported residents' sense of self (Phinney *et al.*, 2007). The care homes were able to encourage some semblance of independence by allowing residents to complete minor tasks. But not every resident was able to or allowed to help, and such tasks did not occur regularly each day. As highlighted in Chapter Five, residents also used independence as a source of social comparison to enhance their sense of self in light of more severely impaired peers, discussed further below.

Sandra (resident, Care Home 01) was a notable anomaly. She was one of the few residents who perceived an improvement in her independence and autonomy following the transition to a care home, and felt a benefit to her overall sense of self. Thus, Sandra did not have to reassess her interpretation of independence and autonomy. This may have been due to her perception that her life prior to the transition to a care home was difficult and marred with negativity, difficulty, and control. Other research has demonstrated that identification to a new social group can improve well-being; if there is perceived compatibility between new and old identities, then a person is more likely to identify with the new group (Iver et al., 2009). Sandra had considered herself to be independent when younger, but her personal circumstances made it difficult for her to enact on this sense of her self, and to form meaningful, identity-relevant networks beyond her immediate family. Therefore, the transition to a care home had two main consequences for her: Firstly, the care home was able to facilitate her sense of self as being independent, which helped her to identify with being a care home resident. Secondly, feeling an identification with being a care home resident provided a sense of belonging and enhanced well-being, which typically comes from categorisation in a social group (Iyer et al., 2009). Furthermore, Sandra, being one of the only residents who wanted to move to a care home and organised the move, may have had an overall more positive transition process than residents who were not involved in the decision, and did not wish to move. This difference in experience may have also influenced her perception of life in the care home.

#### 7.4.2. Social comparison

Individuals have nuanced identities, and can belong to multiple social groups at any one time. The strength of these connections or the active engagement with each social identity is dependent upon the salient social context at the time. For care home residents, the care home context was their salient context, especially because they rarely left that environment to engage with their other social identities (e.g. as a mother, friend, football fan). Findings in the present study suggested that most residents acknowledged that being a care home resident was their new salient social group, and transitioning to a care home was necessary because of their care needs. However, they disliked the negative connotations linked with residency in a care home, because of its association with severely cognitively and physically impaired individuals. Other studies have shown that residents consider those with dementia to bring a stigma on to the ward and physically and socially avoided them (Golander, 1995). For residents in the current study, residing in the same facility as obviously more impaired individuals generated concerns that they would be considered as impaired and dependent as those residents. This made them feel out of place, which has been echoed in other studies (Falk et al., 2012). Being considered "the same as" or "as bad as" residents with dementia was an affront to their established identities. A person's sense of self is not only defined by the social groups to which they belong, but also their differences to other social groups (Haslam et al., 2009). What you are not is almost as important as what you are.

According to Festinger (1954), and authors of SIP, people strive to maintain a positive self-evaluation. Residents without dementias in the present study wanted to avoid having the membership of a negatively perceived social group imposed on them, via symbolically charged interactions with others who may consider them to be 'as bad as' the negative outgroup. Residents without dementia were motivated to create a positive sense of identity in light of their new, negatively-perceived context. As discussed in Chapter One, according to SIP, there are multiple strategies an individual or group can use in order to achieve a more positive sense of identity: social competition, social creativity, and social mobility. The latter involves physically leaving the group, but the residents could not physically leave the care home for a long period of time. Social competition involves group-level action to change the status of the group through direct competition with the outgroup. The

only other option available to the residents was to engage in a social creativity strategy.

Residents without dementia psychologically distanced themselves from residents with dementia via social comparison. Social comparison can be used as a means of cognitive adaptation, used when people feel at risk of loss of their positive selfconcept (Gibbons and Gerrard, 1991). When an individual's self-concept is threatened, they reflect on their abilities and opinions with a relevant comparator group, which is typically worse off. This creates a lower reference point from which to evaluate their current situation. Residents with dementia served as the downward comparison group, i.e. were considered to be worse off because of their advanced cognitive, and sometimes physical, impairments. Such downward social comparisons serve to enhance self-image, and in turn improve well-being. Residents without dementia felt the need to compare themselves to residents with dementia, when they felt at risk of being perceived as equally impaired and therefore 'inferior'. Over the course of the data collection period, residents frequently used this strategy within the majority of observations across the three care homes, illustrating that social comparison remains an important adaptive strategy in older age (Heidrich and Ryff, 1993; Heckhausen, 1999), one that is continuously used over time.

Social comparison can serve two functions: First, it confirms to residents without dementia that they do not belong to the same group of impairment as residents with dementia. Second, verbalising their social comparisons to other people can prompt other individuals to treat them as though they are different. It can be difficult to confirm to yourself that you are part of one group, if other people treat you as though you are in a different group. Again, Cooley's (1922) "looking glass self" is a useful metaphor. Like looking in a mirror, others' perceptions of us are reflected back on to us, so we constantly refer to others when constructing our self-concept (Billington *et al.*, 1998). How we react to those perceptions may differ, but how others perceive us is an important factor in our own self-development. Who these others are will depend on the context and social situation. For residents in the present study, most social interaction occurred with members of staff, other residents, and me, the researcher. Throughout the majority of the data collection period, there were more residents with a form of cognitive impairment in each of the care homes than there

were residents with no form of cognitive impairment. This meant that the latter often had limited interactions with other individuals with no cognitive impairment. Therefore, the members of staff were considered to be an important source of interaction for these residents. Other studies have highlighted the importance of staff for social interaction in care homes (Hubbard *et al.*, 2003; Moriarty *et al.*, 2010; Haugan *et al.*, 2013; Haugan, 2014).This made the members of staff relevant 'others' from which residents gain an understanding of how they are perceived. It was important to residents without cognitive impairment to enhance the perception of themselves as different to other residents.

In the vast majority of cases across the three care homes, residents without dementia displayed frustration towards residents with dementia. Repetitive behaviours, shouting, and wandering are symptomatic of dementia (Alzheimer's Society, 2014a), and long-term exposure to such behaviours became wearing. Expressions of frustration and sympathy towards those with dementia also served to emphasise that they were different, and to psychologically distance themselves from residents with dementia, a strategy outlined in SIP to cope with being in a negatively perceived group (Reicher et al., 2010; St. Claire and Clucas, 2012). Furthermore, many residents with more severe dementia were dependent on staff for most daily activities and general support. Given the importance of independence to their identity, residents without dementia sought to emphasise their relative independence in comparison to residents with dementia. This comparison had the positive consequence of reinforcing their own identities as being independent individuals. From the Social Identity perspective, residents without dementia emphasised a new dimension of comparison (independence and autonomy) that resulted in themselves being perceived more positively than those who were less independent.

Similar acts of social comparison are evident throughout the health psychology literature. For example, breast cancer patients who had lumpectomies positively compared themselves to those who had had mastectomies (Taylor *et al.*, 1983). By comparing themselves to individuals who had a comparatively more negative experience of breast cancer, the lumpectomy patients could feel better about their own experiences. This in turn promotes a more positive identity, because though they could not leave the social illness group of 'breast cancer patients', they engaged

in social creativity to align themselves with a more specific and less negative social group. Similarly, realising that other individuals are feeling worse may help people with depression feel better (Gibbons, 1986). Older people can compare themselves to age-peers, re-interpret their current situations accordingly, and preserve their life satisfaction in the face of age related loss (Baltes and Baltes, 1990). However, the act of social comparison in care homes, particularly using SIP, and how this influences identity, has been unreported in the identified literature.

One criticism of studies on social comparison is that they mostly focused on downward comparisons, and neglect upwards comparisons. Taylor and Lobel (1989) found that people under stress tend to compare themselves with others who are "better off". Such comparisons may serve different needs to downwards comparisons, and suggested that upwards comparisons can help provide information on how to cope with a negative situation by providing hope and motivation. For instance, someone who has cancer could compare themselves with someone without cancer, but feel motivated that they too could beat the disease. Findings from the present study suggest that residents did not engage in upwards social comparisons as readily as they did downward comparisons. There was no evidence of residents across the three care homes comparing themselves to a group that was 'better off'. Residents with cognitive impairments and/or physical impairments did not appear to compare themselves to residents with no such impairments, and residents in general tended not to compare themselves with other older people who were not residents in a care home. One explanation for this could be that there were insufficient examples of upwards comparison groups, i.e. there were very few residents who did not have some form of cognitive or physical impairment in the three care homes. Furthermore, members of staff and relatives may be considered to be too different for residents to make meaningful comparisons. According to SIP, the dimensions of comparisons between in/outgroups must be similar enough to be meaningful to the individual (Jetten et al., 2001; Reicher et al., 2010). An older person in a care home is unlikely to compare themselves to someone who is not older and does not permanently reside in a care home.

#### 7.5. Organisational constraints influence the expression of identity

Moving away from one's home and in to long-term care can be a difficult event for older people. Typically, the aim for residential care was to recreate a sense of 'home' as much as possible (Peace and Holland, 2001; Ryvicker, 2009). However, the appropriateness of attempting this has been questioned (Peace and Holland, 2001; Davies and Brown Wilson, 2007). The findings of the present study have demonstrated that most care home residents did not feel at home in the facilities, whether those residents had recently transitioned to the care home, or had lived there for some time. The care homes were not held in the same regard as residents' own homes, because the facilities did not represent the same associations with family and shared memories, which can be extremely difficult or simply impossible to recreate (Peace and Holland, 2001). Alternatively, others have suggested developing a sense of community in care homes through a relationship-centred approach to care (Davies and Brown Wilson, 2007), but this was not accomplished in any of the three care homes studies. Understaffing and a lack of resources were often cited as the main reason for hurried, sometimes impersonal care.

An individual is relatively free to act autonomously within his or her own home (Maddox, 2003), whereas an "institutional body" is managed through routines, waiting and risk management (Wiersma and Dupuis, 2010). Residents need to feel control over their environments in order to preserve a sense of self (Wellin and Jaffe, 2004), and institutional practices can be changed in order to negotiate this. It has been well documented elsewhere that the organisational features of a care home, including institutionalised routines, can have a negative impact on an older person's well-being and sense of self (Goffman, 1961). This study reflected those findings, whilst adding that the associated routines and restrictions of the care homes can have a negative impact on residents' abilities to express their sense of identity.

Staff in each care home were initially quick to declare that residents could make decisions within the home, from their personal décor to the daily routines. Some staff readily acted on residents' autonomous decisions about their daily care, from amending meal plans to facilitating a 'duvet day'. Such behaviour encouraged residents to enact on their individuality, which made them feel more in control of their surroundings. However, amendments to daily routines to promote independence

and individuality only occurred occasionally throughout the three care homes. Findings echoed sentiments in the literature that suggests that organisational efficiency takes precedence over residents' social and emotional needs (Foner, 1994). Strict routines and the standardisation of care can strip care home residents of their individuality and dignity, and in turn, the expression of their personalities (Goffman, 1961; Diamond, 2009; Ryvicker, 2009). The majority of residents in the current study did not feel in control due to the strict organisation of sleeping, waking, eating and activities. There was little flexibility and limited opportunity to change established routines in order to accommodate individual needs and wants, which was reminiscent of the findings of (Lidz and Arnold, 1992) over twenty years ago, indicating that little has changed for the three participating care homes. According to staff, the flexibility of the routines was limited by the lack of resources and funding.

Observations and conversations with participants across the three homes illustrated that organisational efficiency was inadvertently considered to be more important than individual residents' needs (Foner, 1994). Studies have acknowledged that residents often consider a variety of their needs as unmet in the care home (Hancock et al., 2006; Falk et al., 2012). Having to wait for assistance or being ignored can make residents feel insignificant (Falk et al., 2012). In most cases, the begrudging accommodation of residents' requests was at an emotional cost to many residents, who would reconsider making such requests again. So while staff may have eventually acted upon residents' individual requests, the attitude of the former inadvertently stifled residents' motivations to exert their independence, which was an essential element of their personal identities. This led to feelings of disappointment and frustration across the three care homes, between residents, relatives and staff. Residents voiced disapproval with how often staff and the routine of the home depleted their autonomy and independence, and repeatedly ignored their needs. The longitudinal nature of the observations demonstrated that this was a recurring issue across the care homes.

Care home staff were sometimes in danger of trivializing residents' complaints or needs (Persson and Wästerfors, 2009). Across all care homes, some members of staff stated that they felt some individuals would complain about their care unnecessarily,

had unrealistic expectations of care, and did not have an appreciation for how difficult the caring role was, particularly those with dementia. By labelling residents as such, the care home staff were pre-emptively excusing themselves from making a concerted effort to meet residents' needs and wants. Reminding a resident who was requesting assistance that there were other residents to care for trivializes the feelings of the former, as though their needs are perpetually secondary. Findings demonstrated that while the residents understood how busy care staff were, they felt unsatisfied with how their daily needs were often belittled. This trivialising of needs further undermines their sense of control, and thus autonomy, further undermining an important element of their identities.

There are links between staff and resident relationships identified in the present study, and some elements of Kitwood's 'malignant social psychology'. But Kitwood's work is predominantly on people with dementia, whereas the present study found evidence of malignant social psychology towards all residents, regardless of dementia diagnosis. The elements of malignant social psychology are summarised in Box 4. Residents without dementia in particular tended to stigmatise, psychologically 'banish', and occasionally infantilise residents with dementia, though, as Kitwood (1993) stresses, this is not necessarily done with malice. For residents in the present study, these were techniques to improve their own selfconcept. Staff also had a tendency to disempower most residents, and complete tasks that a resident could have been supported to achieve themselves, and occasionally invalidate residents' feelings regarding their care or independence. As discussed in more detail in Section 7.5.6, some staff engaged in 'treachery', whereby they misinformed or withheld the truth from residents with dementia regarding their false memories to obtain compliance, quicken the pace of care, or lessen the distress of the resident. However, in the present study, most other elements of Kitwood's (1993) malignant social psychology were not readily observed throughout the three care homes. Further, use of such strategies were not as severe as in Kitwood's (1993) descriptions, and there was a general feeling that participants engaged in such practices despite acknowledging that it was probably wrong to do so. It was often seen as the best thing to do at the time.

# Box 5. Summary of Kitwood's (1993, 1997) 'malignant social psychology'

### 1. Treachery:

The use of dishonest representation or deception to obtain compliance.

# 2. Disempowerment:

Doing for a dementia sufferer what he or she can in fact do, albeit clumsily or slowly.

# 3. Infantilization:

Implying that a dementia sufferer has the mentality or capability of a baby.

### 4. Condemnation:

Blaming; the attribution of malicious or seditious motives, especially when the dementia sufferer is distressed.

### 5. Intimidation:

The use of threats, commands or physical assault; the abuse of power.

### 6. Stigmatization:

Turning a dementia sufferer into an alien, a diseased object, an outcast, especially through verbal labels.

### 7. Outpacing:

The delivery of information or instruction at a rate beyond what can be processed.

### 8. Invalidation:

The ignoring or discounting of a dementia sufferer's subjective states – especially feelings of distress of bewilderment.

### 9. Banishment:

The removal of a dementia sufferer from the human milieu, either physically or psychologically.

# 10. Objectification:

Treating a person like a lump of dead matter; to be measured, pushed around, drained, filled, polished, dumped etc.

### 11. Ignoring:

Carrying on (in conversation or action) in the presence of a person as if they were not there.

### 12. Imposition:

Forcing a person to do something, overriding desire or denying the possibility of choice on their part.

### 13. Withholding:

Refusing to give asked-for attention, or to meet an evident need.

## 14. Accusation:

Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.

# 15. Disruption:

Intruding suddenly or disturbingly upon a person's action or reflection; crudely breaking their frame of reference.

# 16. Mockery:

Making fun of a person's 'strange' actions or remarks. Making jokes at their expense.

### 17. Disparagement:

Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self-esteem.

The attitudes of staff towards individual requests were related to their perceived stress-levels and busyness of the care home. They blamed organisational limitations, limited resources, and a demanding schedule on their inability to accommodate autonomous decision-making within the home. Such issues have been highlighted elsewhere (Persson and Wästerfors, 2009), and is an ongoing contentious issue in discussions of long-term care. To assuage some of the pressure from these issues, staff emphasised the necessity of residents to adapt to the routines of the care home to also manage residents' expectations of care. Routines should be adhered to in order for staff to complete their tasks efficiently and on time for other residents, and reduce the risk of being reprimanded by superiors. This was understandable to a degree. The care homes were often understaffed and staff often lamented the lack of resources to accommodate individuality in routines, to such an extent that staff in Care Home 02 claimed they could not afford a new book of word searches for a resident.

While being understaffed and under resourced appeared to be genuine issues across the care homes, it sometimes felt as though these were easy excuses. Larger tasks, such as days out, obviously take a lot more funding and staff to organise and accomplish. However, making coffee instead of tea takes little additional effort, and these minor changes, such as a duvet day, were small ways that made resident feel more comfortable and able to exert their independence and autonomy. Staff in Care Home 03 were able to accommodate individual residents requesting hot drinks whenever they wanted one without any obvious strain on resources. Such efforts helped to enforce residents' sense of independence and autonomy, which was so important to their sense of identity.

#### 7.5.1. Relationships between staff and relatives

Findings from the present study reflected those that suggested relationships between staff and relatives were largely superficial (Hertzberg and Ekman, 1996). A lack of communication between care home staff and residents' relatives has been cited elsewhere as a cause of friction, and can result in important information not being exchanged (Brown Wilson, 2007; Utley-Smith *et al.*, 2009). Relatives and staff occasionally demonstrated different interpretations of the caring role. Although

relatives initially voiced how impressed they were with the care in the care homes, they also highlighted that much more could be done to improve the residents' experiences. Relatives and staff occasionally had disagreements over elements of the residents' care, both in terms of their physical care needs, and the individually orientated, person-centred care provided. One tended to suggest that the other expected too much and did too little. Similar to residents, relatives felt that staff could do more to incorporate individuality in daily care, such as through dress and décor of the bedrooms, and generally improving care. According to staff, infrequent visits and a poor understanding of the caring role was a reason for this frustration. Given the lack of visitors across the three care homes during the data collection period it was difficult to obtain more opinions from relatives on the matter, which ultimately confirmed staffs' perceptions of relatives' efforts to remain involved in residents' care.

Relationships between residents, relatives, and staff are a key determinant of experiences in care homes (Bowers *et al.*, 2001; Brown Wilson, 2007). Authors of the *My Home Life* review, amongst others, have emphasised the importance of creating a sense of community within the care home with residents, relatives and staff (NCHR&D, 2006; Davies and Brown Wilson, 2007). In the present study, some relatives maintained a positive relationship with staff, and both felt able to voice concerns with the other. For others, infrequent and irregular visits hampered the development of a strong relationship with care home staff, which ultimately affected communication between the two. Furthermore, lack of communication between relatives or significant others and members of staff made it difficult for the latter to learn the important, idiosyncratic information about the resident, particularly those with dementia who could not provide this information themselves. It was therefore difficult to ensure that staff were aware of the identity-relevant information in order to incorporate this in to daily care.

#### 7.5.2. Lack of social interaction

Long-term care facilities have been described as "non-places that afford few links with one's personal or cultural past" (Chaudhury, 2003: 88). Residents' social relationships, access to personally and culturally relevant objects and routines, and sense of control were all impacted by life in the care home. Findings of the present study confirmed that residents experience a loss of important relationships following the transition to a care home (Tester *et al.*, 2004), as participants received very few visitors over the data collection period. Consequently, participants experienced a disconnection from their significant others. Interactions are relevant for self-categorisation and confirming our identities (Swann and Read, 1981; Swann and Hill, 1982; Billington *et al.*, 1998; Reicher *et al.*, 2010). Maintaining links to relevant social groups provides a sense of belonging and helps to buffer a threatened well-being when faced with being a member of a negatively perceive social group (Haslam *et al.*, 2009).

A study by Cohen-Mansfield *et al.* (2000) suggested that care home staff believed regular visits from family to be important for the enhancement of residents' identity. This is particularly true for residents with dementia, who have an increasingly weakened grasp of important identity-defying memories associated with significant others (Cohen-Mansfield *et al.*, 2000; Jetten and Pachana, 2012). The SIP highlights the importance of social interaction within a particular context in the development of identities (Reicher *et al.*, 2010). Residents who received few visitors from significant others thus lacked the necessary interactions to reinforce their identities. Someone who takes pride in an aspect of their personality cannot do so without contact with others who acknowledge this personality trait and act upon it.

While residents were reluctant to criticise their families for not visiting, it became clear through observations and conversations with staff that residents who received regular visits settled in to the care home better and were considered to be happier than those who did not receive visitors.

Following the transition to long-term care, Falk *et al.* (2012) suggests that residents should "bridge the gap" between their old and new self-identities by creating attachments beyond the institution. However, the residents in the three participating care homes in the present study had no such opportunity to establish connections beyond the care homes or to maintain pre-established connections. To counter this, residents could establish meaningful connections within the care homes in order to forge new identities or maintain established self-concepts. Studies suggest that

residents value the opportunity to develop friendships with other residents (Mattiasson and Andersson, 1997; Tester et al., 2004; Davies and Brown Wilson, 2007). However, other studies have found that non-intimate relationships are common in care homes (McKee et al., 1999), and the present study echoes this; residents rarely conversed or formed meaningful relationships with one another. While some argue that this rarely happened because opportunities to establish relationships were limited (Mattiasson and Andersson, 1997), observations in the present study suggested that residents had the opportunity to engage with one another, but chose not to. Residents only occasionally conversed during organised activities, which were themselves rare, and such interactions did not last beyond the activities. The quality of relationships within residential care affects the maintenance of self (Rogers and Stevens, 1967) and residents' perceived quality of life (Tester et al., 2004; Surr, 2006). The persistence of non-intimate, or simply non-existent relationships in the care homes could have an impact on residents' maintenance of self or quality of life, as they cannot form meaningful relationships within which they can co-construct their sense of self. There are also implications for their wellbeing (Jetten and Pachana, 2012).

Impairments served as a barrier to forming new relationships within the care homes, with residents acting sympathetic or hostile towards residents with cognitive impairments, as has been illustrated elsewhere in the literature (Tester *et al.*, 2004; Surr, 2006). Being unwilling to form relationships with other residents with dementia may have been protective, to avoid others perceiving them as 'the same', or themselves feeling as though they were in the same group as residents with severe cognitive impairments. Returning to the notion of physically and psychologically distancing oneself from a negatively perceived group in order to protect ones comparatively positive sense of identity, outlined in SIP.

It was unclear why residents with no cognitive impairments did not engage with one another more often, especially as many expressed feelings of loneliness. Of course, a meaningful friendship might not necessarily stem from having similar cognitive and physical abilities; there may have been individual differences based on personality that made some residents without impairment feel disinclined to regularly interact with other residents without impairment. Again, most residents across the three care homes had a form of cognitive impairment, so residents without severe impairment had few people who they could converse with, of whom they might not have had much else in common. Furthermore, participants indicated that residents might not have formed friendships due to an awareness of their own mortality, and an unwillingness to form a connection with someone who may soon die or develop dementia, and the subsequent necessity of coping with that loss.

#### 7.5.3. Activities, hobbies, and personal décor

Engaging in meaningful activities is one way to maintain self in long-term care (Tester et al., 2004; Cohen-Mansfield et al., 2010). Older people experience the reduction or loss of long-standing, meaningful activities, but the sense of identification with these activities can continue in adapted ways of living (Jetten and Pachana, 2012; Lloyd et al., 2014). Changes to activities that were apparently at a superficial level were actually important to participants' sense of self, such as giving up driving over safety concerns following declining eyesight (Jetten and Pachana, 2012; Lloyd et al., 2014). Like in Lloyd et al. (2014), participants across the three care homes maintained their sense of identification with certain activities via adapted ways. Residents in the present study highlighted how their choice of activities and hobbies changed as they got older, but activities were still broadly related to each other; for example, changing from participating in dancing to just watching; from knitting to crocheting due to arthritis. However, there was ultimately a feeling of loss following these amended activities. This demonstrated the continued importance of particular activities for older people, though the transition to a care home dramatically reduced the residents' opportunities to engage in even their adapted activities.

Activities need to maintain, expand or respond to an area of interest, as those with current interests in certain activities are more likely to engage in those activities if offered in the care home (Cohen-Mansfield *et al.*, 2010). Residents, relatives and members of staff may have differing interpretations of what constitutes an appropriate activity. For residents with dementia, activities are considered to be meaningful when they are based on past roles, interests and routines; so in essence reinforcing their sense of identity and belonging (Harmer and Orrell, 2008). Residents themselves considered activities to be meaningful if they address

psychological and social needs, whereas family carers and staff tend to focus on the physical needs of a resident (Harmer and Orrell, 2008). In the present study, not all the activities offered in the care homes suited each resident. It was difficult to organise relevant, meaningful activities given the lack of resources and limited staff. Across the care homes, only one activity was arranged that responded to residents' specific interests, which previous studies have identified as important for residents and staff to form relationships (Cook and Brown-Wilson, 2010). Other activities were organised based on a general assumption that they would be enjoyable, or the "headline" activity, for instance, that residents enjoyed music, so a music activity was arranged, regardless of the type of music the residents enjoyed.

Studies have identified a lack of meaningful activities in care homes, particularly for people with dementia (Harmer and Orrell, 2008). In 1974, Gottesman and Bourestom (1974) reported that nursing home residents spent 56 per cent of their day doing nothing, and according to more recent studies (Ice, 2002; Davies *et al.*, 2005), residents still spend most of their days passive "inactive, immobile, and alone" (Ice, 2002: 345). The longitudinal observations for the present study echoed these findings. The residents sat for the majority of the day, usually in front of the television, and did not converse with one another. In a study by Cohen-Mansfield *et al.* (2000), TV watching was the most common present leisure activity in which residents participated, according to staff. Though observations echoed this, there were few other options available. Past leisure activities mentioned by participants in the current study, such as music, reading, cooking, dancing and gardening, were not available for any resident, regardless of impairment, unless they or a family member arranged it themselves. Activities could enhance the identity of residents with dementia (Cohen-Mansfield *et al.*, 2010) and without dementia.

Lack of meaningful activities in care homes in the study was blamed on organisational issues and too few staff, so everyday activities tended to be monotonous and poor quality, such as watching TV. Though questions about meaningful activities were included in residents' initial care plans upon arrival to the care home, there was little evidence that staff incorporated this knowledge in to their care. Similar to findings in Tester *et al.* (2004), staff argued that residents did not want to engage in any organised activities. Upon further reflection, residents'

disinterest with organised activities could be due to their irregularity. If activities were more regular and part of the everyday routine, then perhaps residents would be more interested and enthusiastic about participating.

It is also reported elsewhere that residents rarely leave the care institution (Tester *et al.*, 2004), and can often feel bored and under stimulated. This was true across the three care homes in the study; residents very rarely went outside the institution, and felt bored. A connection to the outdoors plays a role in their quality of life for many reasons, including stimulation, providing opportunities to engage with neighbourhood and community, contact with wildlife, fresh air, and exercise (NCHR&D, 2006; Falk *et al.*, 2012). Having insufficient resources to facilitate a day out severely restricted the options residents had for meaningful activities to those that could be conducted within the facility. Any meaningful activities that required leaving the care home were therefore immediately prohibited unless relatives took on the responsibility to organise such an excursion for their own family member. Residents with no such social network were at a disadvantage.

#### 7.5.4. Possessions

"Our fragile sense of self needs support, and this we get by having and possessing things because, to a large degree, we are what we have and possess"

(Tuan, 1980: 472)

Major relocations and transitions, such as moving to long-term care, involve the loss of many personal possessions (Bridges, 2007), and in essence, the loss of self (Belk, 1988). A symbolic interactionist/social constructionist perspective focuses on the exchange of information between people when they interact. Inanimate objects are important in a discussion on identity and personality, and the literature identifies a connection between possessions, personalities, and identities. Possessions enable a person to express their identity and personality (James, 1890; Wallendorf and Arnould, 1988; Cram and Paton, 1993; Kroger and Adair, 2008; Gosling, 2009) and can demonstrate a connection to other social groups or members of society (Wallendorf and Arnould, 1988). Valued possessions can remain important throughout the lifespan (Rochberg-Halton, 1984; Chapman, 2006; Kroger and Adair, 2008), and are particularly important in later-life for older adults who had moved to long-term residential care (Erikson *et al.*, 1986). Possessions can help to make a new environment more familiar, particular in light of such a substantial change (Young, 1990). With the gradual loss of friends and family, abilities and social contexts, personal possessions can anchor an individual's sense of identity (Rubinstein, 1987; Kroger and Adair, 2008). The findings of the present study confirmed this, as residents often discussed the significance of a variety of possessions as symbols of their identity. Possessions symbolised important others, such as gifts from friends and relatives, which is echoed elsewhere in the literature (e.g. Belk, 1988).

Most of the resident's belongings had to fit in their bedrooms, which were typically small (Dudman, 2007). The loss of personal items due to the transition to long-term care signified the loss of identity-relevant memories. One way to illustrate the importance of possessions for the self is in studies that document the separation of individuals from their belongings. Goffman did this when he referred to the "personal defacement" of one's "identity kit" (Goffman, 1961: 30) following the transition to an institution. "Possessions are a major contributor to and reflection of our identities" (Belk, 1988: 139), and therefore the loss of possessions can signify a lessening of self (Belk, 1988). Moving to long-term care can entail the loss of personal possessions, which can in turn disrupt residents' connections to these memories and identities (Mountain and Bowie, 1992; Fairhurst, 1999).

Personal possessions serve as aide memoirs; they can serve as cues to invoke memories of the past and past self-identities (Cram and Paton, 1993; Ash, 1996; Phenice and Griffore, 2013; Buse and Twigg, 2014). For instance, a trophy can represent an individuals' sporting self (Cram and Paton, 1993), even when that individual cannot play sport anymore. Julia's (Care Home 01) sewing machine anchored memories of a strong business woman in a loving relationship. Using possessions as repositories for memories is particularly important for residents with dementia (Buse and Twigg, 2015b). Relatives and residents regularly emphasised the importance of displaying photographs, as they feared the resident would forget who the people in the photographs were, eroding that individual's personhood.

While the importance of possessions for care home residents is described elsewhere in the literature (Young, 1990; Cram and Paton, 1993), this study further supports the notion that personal artefacts were essential for care home residents to anchor their personalities and personal identities. Without such possessions, the participants lacked 'evidence' for their personal and social identities. Consequently, the residents were at risk of forming a negative self-concept without the positive reinforcement of meaningful possessions, and the act of remembering and storytelling to confirm their identities with others.

Residents are in a setting that is controlled and designed by others, which does not necessarily reflect themselves, or their identities. Homogenously decorated bedrooms and communal areas, or a relative lack of private spaces can jeopardise a residents' sense of identity (Bridges, 2007). According to Falk (2012), adjustment to, and creating a sense of home within residential care encompasses three dimensions: attachment to place, to space and attachment beyond the institution. This involves personalising the environment by adding possessions and furniture etc., in order to transform a resident's private space in to a haven of familiarity. All the care homes in the present study stated that a resident could decorate their rooms if they wished to do so, and enabled residents to bring pieces of furniture if there was room. However, in practice, residents were afforded minimal opportunities to truly transform their rooms, with some being unable to bring any furniture with them at all. This limited the ability of the residents to adequately "nest" (Falk, 2012), and use their rooms, their only source of privacy, to reflect their personalities.

Like possessions, clothing is also important for the 'presentation of self' in everyday interactions (James, 1890; Goffman, 1959; Twigg, 2013; Twigg and Buse, 2013; Buse and Twigg, 2015a). Identity is "performed" through dress (Buse and Twigg, 2015a); and remains important for older people with dementia, as they retain a sense of their personal style (Buse and Twigg, 2015a). Clothes can trigger memories when touched or worn, and serve as "vehicles for selfhood" (Hoskins, 1998; Twigg, 2013). Although Twigg and colleagues focus on the continued importance of clothing for people with dementia, similar themes were also salient for residents without dementia in the current study. The present study confirmed findings that suggest clothing is significant for an individual's personal biography (Woodward, 2007), as

they represented memories, embodied identities and personal narratives for many residents across the care homes (Hockey, 2012; Buse and Twigg, 2015b).

The ageing process can influence how an older person dresses, with their changing bodies and abilities. However, the care setting can often influence residents' access to clothing, and how care staff dress residents (Buse and Twigg, 2015a), as was demonstrated in the present study. Many residents lost or had to abandon clothing during the transition to the care home, which limited their choices of what to wear. Only residents who were very physically able or who had relatives who visited regularly to bring them clothes were able to dress as they pleased. Physically or very cognitively impaired residents, who were unable to dress themselves, were reliant on relatives and staff to engage in what Crichton and Koch (Crichton and Koch, 2007) 365 called "curating" identity on their behalf, through dress.

Understanding the clothing preferences of a resident is an indicator for good personcentred care (Brooker, 2007). With feedback from relatives, the staff can help to maintain permanence of the self and biographical continuity (Ward et al., 2008; Ward et al., 2014), as was demonstrated in the present study where relatives reminded staff how the resident preferred to dress. To a degree, this was achieved. However, as care needs increased, staff tended to favour dressing residents in loser fitting and easy-to-clean clothes, or "babywear" (Twigg and Buse, 2013: 330), despite this ignoring some residents' embodied identities (Buse and Twigg, 2015a). Other studies have highlighted the tensions that arise when care needs outweigh the desire for continuity of the self (Ward et al., 2008). Dressing a resident in a skirt rather than trousers, because it was easier to change and wash her after she soiled herself is not taking in to consideration that resident's personal identity. Residents' and relative's insistence that such clothing was 'not them' demonstrated that the new enforced outfits did not reflect their personalities. This issue also highlighted the differences in expectations of care between residents, relatives, and staff. Insisting that a resident wear a co-ordinated outfit might be putting unnecessary strain on an apparently already overstretched workforce.

Given the significance that most residents and their relatives placed on appearance, particularly in relation to clothes, clothing impacted self-perception within the care home. Not only did it stifle the expression of residents' own personal and social identities, but a comparatively dishevelled appearance embodied the negative identity of being a care home resident with dementia, as the neglect of appearance is considered to be a sign of dementia (Jenkins and Price, 1996). This was a prevalent fear for residents without dementia in each care home, particularly for those for whom being smartly presented was a significant part of their personalities. As discussed further in Section 5.4, residents did not want to be associated with those with dementia out of concern that others would consider him or her to be as dependent and "useless" as they considered residents with dementia to be. From a symbolic interactionist perspective, clothes reflect our personalities and influence how others perceive us (Goffman, 1959). Appearing to wear the "uniform" of a negatively perceived outgroup is likely to influence others' perceptions of that resident, and the present study, that caused some residents distress.

Residents and relatives also experienced some distress when staff dressed residents with dementia in someone else's clothing, or when the resident with dementia unintentionally stole someone else's belongings. Residents' and relatives' reactions were akin to those Belk (1988) describes following a theft or burglary. By dressing one resident in someone else's clothes, the staff were inadvertently (temporarily) giving away a meaningful possession; one that encompassed memories, feelings of security, and identity (Belk, 1988). Relatives considered this an affront to the individual to whom the object belonged. Being outwardly unconcerned with ownership and the emotional significance of seemingly insignificant items essentially whitewashes residents' personalities, reducing them to paper dolls with interchangeable selves. However, by unintentionally stealing someone else's jewellery and verbalising her love of accessories and associated memories, Alwen (Care Home 01, resident) was able to alert the staff to which items were important to her sense of self, but which she had no access to. By giving her jewellery, staff were able to first, reduce the likelihood that she would steal from someone else again, and second, enabled her to display an element of her personality (and thus her personal identity) that was previously limited by the absence of such items in her own room.

#### 7.5.5. Food and identity: Personal and cultural differences

Mealtimes were a significant event within the care homes, as it involved most staff who were on shift assisting the residents at once. Any change or issue could affect the efficiency of the rest of the service. Food and meal preparations are one of the many ways that an individual can express their individuality, personality and cultural differences (Fischler, 1988; Verhagen, 2012; Almerico, 2014). Food can reflect a person's "extended self" and alignment with particular social groups and cultures (Belk, 1988). It can also serve as an anchor to important memories, much like Joan's jam sandwiches (Care Home 01), which anchored past memories of childhood and life before the care home, and still provoked gleeful enjoyment even as her dementia progressed.

The NHS Choices (2015) and Care Quality Commission (2015) state that a good care home should take into consideration residents' ethnic, religious and cultural background when organizing care, including meals. However, the daily traditional British menus of each care home failed to adequately fulfil this; although such menus were a common occurrence across care homes in Manchester (Wasielewska et al., 2012). This is in contrast to the CQC's (Care Quality Commission, 2013) findings of 98 per cent of homes inspected meeting residents' dietary requirements based on their religious or cultural backgrounds. For the present study, this suggests that residents from other countries and cultures were denied the opportunity to express their social and cultural identities within the care home during mealtimes. Regularly meeting individual desires at mealtimes, including culturally-specific cuisine, can be time consuming and costly, as not every individual resident can have a specific meal made for them every day. There are also nutritional concerns to consider, as culturally relevant food may not be healthy for a particular resident. However, there was a definite feeling that more of an effort could have been made to embrace individuality whilst taking these issues into consideration.

Although there was no formal data collected on participants' cultural backgrounds or ethnicities, discussions with participants led to the conclusion that the majority of residents interviewed were white and British. No residents were interviewed who were from other cultural backgrounds, due to an inability to obtain consent, and language difficulties. Therefore, while the findings of the present study suggest that residents enjoyed the food, this may have been because the care homes served the type of food they were used to, and had enjoyed prior to their transition. If more residents of different ethnicities or cultural backgrounds were able to participate, then they may have provided more information on the inclusion of culturally diverse practices within the care homes.

## 7.5.6. False memories: Ethics and identities

In the present study, there were tensions with staff and residents without dementia, as to the appropriateness of addressing the false memories of residents with dementia. This again raises similarities with Kitwood's malignant social psychology, particularly the element of 'treachery', whereby a person is dishonest to another to obtain compliance. Carers sometimes lie to people with dementia out of concern for their best interests, though the circumstances under which it is acceptable to lie to a person with dementia can vary (Elvish *et al.*, 2010; Tuckett, 2012). In the present study, it was easier for members of staff to lie to residents with dementia about their false memories because it was quicker and easier than telling them the truth.

Our experiences and memories help to shape us as individuals and to form our identities. Autobiographical memory is important for older peoples' self-knowledge from the past and present, in order to maintain the continuity of identity (Addis and Tippett, 2004). Often, those suffering from Alzheimer's disease have to be reminded of identity-relevant, biographical information, and their significant others (Caddell and Clare, 2010). Therefore, the loss of autobiographical memory can affect an individuals' sense of identity (Hirst, 1994; Jetten *et al.*, 2010), particularly when the impairment is to autobiographical memories of childhood and early adulthood (Addis and Tippett, 2004). As person must be able to draw on previous information about themselves in order to provide a sense of continuity, as well as incorporating contemporary information in order to revise their sense of identity (Baddeley, 1992;Naylor and Clare, 2008). These studies utilise different interpretations of identity, with many quantitively measuring the concept.

An interference with recall of self-knowledge can lead to 'imaginary identities' (Crisp, 1995; Cohen-Mansfield *et al.*, 2000). This has important implications for the

identities of residents with dementia, and emotionally for their relatives. Residents in the study were shown to draw feelings of pride and accomplishment based on their false memories of childhood and early adulthood. They were also emotionally invested in their false understandings of reality. If individuals draw on selfknowledge spanning their life course in order to form their social and personal identities, i.e. which groups they belonged to, what they did as an occupation or memories reflecting personality traits, then those who draw on their false memories are at risk of developing an identity based on 'shaky' foundations. However, this is likely to only be a problem if the resident is challenged on their false memories.

In the present study, there were tensions with staff and residents without dementia, as to the appropriateness of addressing the false memories of residents with dementia. On the one hand, some believed that, ethically and morally, they should remind residents with dementia of reality. Failing to do so could lead to expectations based on those false memories, for example, that Alwen's husband was going to collect her from the care home. Hence why Alwen regularly became upset with members of staff, because she continuously assumed that they were breaking their promise to her that her husband was going to collect her. On the other hand, staff put forward the argument that even if they did remind them of the truth, the resident would forget almost immediately, but still become upset, only to forget why they were upset. Also, given the residents' often fervent belief in their false memories, telling them anything different would cause conflict and further confuse the resident. Similar to the findings of (Tuckett, 2012), lying to residents with dementia was sometimes considered to be therapeutic by care providers in residential aged care facilities. So each of the care homes experienced a stalemate where staff and other residents approach the matter inconsistently; sometimes reiterating reality to residents with dementia, and other times agreeing with them.

#### 7.6. Strengths and limitations

The present study achieved many of the quality criteria for qualitative research, as discussed in Chapter Four (see also Table 4). A thick description of the phenomena under study attained with the triangulation of suitable qualitative methods enhanced the transferability, dependability, credibility, and confirmability of the data (see Lincoln and Guba, 1985; Baxter and Eyles, 1997; Reid and Gough, 2000; Shenton,

2004; and Yin, 2009). Methodological decisions have been justified in Chapters Three and Four, and were appropriate to achieve the aims of the study. Although the data were obtained from a single researcher, a consistently reflective approach and regular liaison with participants, and feedback from the supervisory team, achieved referential accuracy. A clear audit trail of data collection and analysis has been presented to enhance the confirmability criteria of qualitative research.

This study initially aimed to have included additional care homes in order to more comprehensively compare and contrast the emerging themes. However, many care home managers were reluctant to participate over fears of 'Panorama style' coverage of their care homes, which would focus solely on any negative findings. Managers were also reluctant to participate because of concerns the study would impact staff performance, despite myself and the Participant Information Sheets emphasising that any interruption would be minimal.

The pros and cons of a smaller number of in-depth cases versus a larger number of more representative cases has been discussed extensively throughout qualitative research (Cleary *et al.*, 2014). The smaller number of care homes involved was actually a strength of the study. It enabled a more in-depth exploration of each case study, and more detailed observations to understand and engage in the context. A smaller sample also enabled a larger volume of time with each care home. Very few qualitative studies have spent over 260 hours over one year collecting qualitative data in this population. Such a longitudinal approach meant that changes over time could be observed and discussed with participants, such as the impact of changing management or newly admitted residents. Furthermore, the length of time spent in each care home allowed me to establish positive relationships with participants, which made them feel more comfortable with disclosing personal information or controversial opinions with me, with the knowledge that such a disclosure would not be abused.

An additional limitation was the absence of purpose-built care homes. Again, despite efforts to recruit such care homes to the study, they declined the opportunity to participate. Future research in this area should include a larger variety of types of care homes in order to explore whether differences in physical environment has any impact on the issues addressed.

Very few relatives were included in the study, which made it important not to make too many assumptions based on the few interviewed. However, this was an artefact of the contexts of the care homes, and not actual issues with recruitment. The fact that so few relatives were included is an interesting observation in itself, and served to highlight the importance of maintaining relationships between residents and their relatives within long-term care.

The study included no formal data on the socio-economic background or ethnicities of participants. Others have demonstrated the influence that class has on identity and how this identity is performed (e.g. Veblen, 2005). More detailed information on the socio-economic background of residents may have added an additional avenue for interpretation of residents' behaviours in the care home. Furthermore, most residents who were interviewed were white and British; the majority of care home residents who appeared to have different ethnicities or cultural backgrounds were not able to participate. Including more residents of different ethnicities and from different cultural backgrounds may have provided information on how care homes incorporated cultural diversity in daily practices, and how this impacted those residents' sense of identity. Though this limitation is a product of the environment, future research on identity in care homes could focus on exploring perspectives of residents from a range of backgrounds.

The majority of participants were women, which is unsurprising given the welldocumented statistics of gender ratios in care home populations (Office for National Statistics, 2014). A larger number of care homes may have afforded the inclusion of more male participants in order to include issues relating to gender in the analysis. It was difficult to do so in the current study because there were few male residents, and fewer who were either eligible or who agreed to participate in the study. A study by Campbell (2012) has focussed solely on men in care homes, with interesting results relating to masculinity in a predominantly female environment. Additionally, though the gender gap within care homes has narrowed between 2001 and 2011, women still represent a larger proportion of the care home population (Office for National Statistics, 2014). In 2011, there were approximately 214,000 women residing in care homes in the UK in comparison to 77,000 men, aged 65 and over (Office for National Statistics, 2014).

#### 7.7. Contributions of the study

The present study demonstrated that care homes residents without dementia engaged in social comparison with care home residents with dementia in order to promote a positive self-concept. These findings confirm established protective strategies highlighted in SIP and social comparison research. However, systematic searches of the literature did not uncover studies that demonstrated such findings within a care home context, particularly focussing on the aim of maintaining a positive identity. Therefore, the present study contributes to the established identity and social comparison literature, but offers a unique insight within an under-research context.

This study has demonstrated that independence and autonomy were important elements of residents' identities, and that for most participants, the transition to a care home jeopardised this. Consequently, residents amended their interpretations of what constituted independence, and engaged in social comparison with lessindependent residents. Being independent and autonomous had changed from being able to autonomously make their own decisions and independently act upon them, to being physically able to engage in tasks within the care home. Other studies identified in the current literature had not discussed the changing nature of autonomy and independence for care home, particularly from an identity perspective. The findings of the present study provide an alternative interpretation of the nature of independence and autonomy within the care home, and using SIP offers potential explanations or interpretations for these findings, which is currently limited within the identified literature.

Longitudinal observations, along with semi-structured interviews, collected over approximately one year stimulated a depth of data regarding the concept of identity in care homes, that was wanting in other identified studies. Furthermore, the use of SIP has been largely neglected from research based in care homes for older people, with the notable exceptions of work by Haslam and colleagues (Haslam *et al.*, 2014). Thus the present study explores the under-researched area of identity within care homes using an effective, yet neglected, theoretical approach. Moreover, as addressed in Chapter Two, very few studies explored the concept of identity in care homes by including the equally valid interpretations of care home residents, their relatives, and members of staff at the care home. By incorporating multiple perspectives, the present study aimed to present findings that could potentially inform and improve care for residents whilst taking in to consideration the issues raised by other stakeholders. Implications for practice, policy, and theory are discussed further below.

#### 7.8. Implications for practice and policy

Despite the fact that policy and guidelines promote the inclusion of identity-based, or biographical information in residents' daily care through person-centred care, the findings of the present study demonstrated that this did not occur very often, or consistently. This perhaps suggests that the current policies and guidelines around maintaining identity in care homes many not be workable for some care home staff. Many participants across the three care homes expressed concern over a lack of resources and funding. Being understaffed meant that the staff on shift felt too pressured to spend more time either learning about residents' identities, or incorporating their knowledge in to the daily care. A lack of financial resources also made it difficult to organise meaningful activities for multiple residents, so staff tended to organise activities that they felt were most likely to please the majority of residents, leaving the minority without adequate activities or entertainment. On the one hand, this reflects various reports that criticise underfunded care facilities, and confirms the need for more funding. On the other hand, making small changes to the daily routines, such as making coffee instead of tea, or facilitating a 'duvet day', takes comparatively little time, effort, or resources. Findings suggested that such allowances meant a lot to residents, and enabled them to exert their independence and autonomy, and express their personalities. Perhaps one issue relates to the training or education of care home staff in facilitating identities within the care home, rather than solely on the issue of funding.

There may be a need for training on how members of staff can incorporate small, seemingly minor changes to residents' daily routines without feeling frustrated, overstretched, or pestered by residents or their relatives. Not all changes to routines

or activities require substantial resources and time. Emphasising why such changes could make a difference to residents may stimulate other members of staff to make an effort to learn identity-relevant information about a resident and incorporate this in their daily care and interactions. However, members of staff who participated in the present study were aware that they should acknowledge residents' individuality, but failed to do so consistently due to a perceived lack of resources to accommodate even small changes. Training may help staff to learn of the various ways that they can acknowledge individuality that does not exhaust resources. An 'identity champion' based in the care home could encourage other members of staff to facilitate individuality. The 'dementia friends champion' training programme has helped others to learn more about dementia, what it is like to live with dementia within the community, and how they could help a person living with dementia in order to create 'dementia friendly communities' (Alzheimer's Society, 2015). A similar programme relating to identity could be useful within long-term care facilities for older people with or without dementia. Incorporating training alongside an 'identity champion' many help to keep residents' individuality at the forefront of daily care.

More could be done to support residents' independence within a care home. Helping residents to complete small tasks for themselves could greatly improve their sense of independence, which the present study has demonstrated was an important element of their identities. However, this would likely involve care home staff spending time with residents to ensure that tasks were completed safely, which again raises the issue of staffing and resources.

Residents, and sometimes staff, would become frustrated with the symptomatic behaviours of residents with dementia, and those with mental health problems or learning disabilities. Perhaps providing residents without such impairments more information about dementia, learning disabilities or mental health problems would increase their understanding and lessen their frustrations. Residents' frustrations over symptomatic behaviour also motivated them to distance themselves and engage in social comparison, in order to avoid being considered the 'same' as those with cognitive impairments. Learning more about the various impairments may help residents without dementia to confirm to themselves that they are not 'the same', thus reducing their perceived need to distance themselves from impaired residents, and therefore motivate them to interact with them socially within the care home. This would benefit all participants, as findings indicated that many residents felt lonely and that they had no friendships within the care home.

The confusion and frustration over how to address the false memories and imaginary identities of residents with dementia suggests that care home staff may need further ethical guidance and training. Tuckett (2012) draws similar conclusions.

Evidence suggests that interventions may be useful in maintaining or increasing a shared sense of social identity within a care home (Knight et al., 2010; Haslam et al., 2014). This may subsequently improve well-being and support the formation of meaningful friendships within the facility. In light of the findings of the present study, engaging residents in group-based biographical work together may help residents to learn more about one another, particularly if they are disinclined to engage with one another socially. This could not only help residents without cognitive impairments to see the other residents as more than their symptoms, but may also stimulate more social interaction and friendships amongst residents who receive few visitors. This suggestion echoes the work of Kitwood, who advocates that carers see the 'person behind the patient' (Kitwood, 1997). Maybe care home residents would benefit from doing the same. Nonetheless, it is impossible to remove all traces of conflict from an environment, regardless of how understanding persons may be of others' impairments. Hence why it is still important for care home staff to support residents to feel comfortable within the care home, particularly at times when they may feel overwhelmed or upset. Organising meaningful activities, or helping to create an environment that reflects residents' personalities and memories, may help to achieve this.

Residents' bedrooms are their only private space in a care home, and findings suggested that they were not adequately decorated. Though the size of the rooms restricted what could be taken in to the care home, there were no instances of the bedrooms being decorate to the residents' tastes beyond what relatives could achieve through photographs and other possessions. While it may be difficult or costly to accommodate a variety of aesthetics within a care home, more could be done to help

residents and their relatives create a comfortable, meaningful environment for residents. Furthermore, care home staff should acknowledge residents' sense of personal style, and resist the urge to dress residents in 'babywear' to make the caring role easier. This should obviously be in consultation with the resident and/or their relatives, as styles many change over time.

## 7.9. Future research

Future studies could attempt to replicate the findings of the present study by including a wider variety of care home types, including purpose-built facilities. As discussed, no purpose-built care homes agreed to participate in the study, though they may have provided an alternative insight into identity in care homes. A different physical environment may influence the experiences of care homes residents, or the day-to-day running of a care home. Additional studies could also include facilities in other geographical locations, possibly with the intention of adding care homes with a more ethnically diverse population.

An intervention study could test the success of the introduction of an 'identity champion' in a care home, or multiple care homes. For instance, an intervention could compare residents' perceptions of their identity, or their feelings towards the inclusion of identity-relevant information in daily care, before and after the introduction of an identity champion in to the care home. Such data could be obtained qualitatively, similar to the present study, whereby residents are interviewed and/or observed at particular points of the intervention. Alternatively, the impact could be measured quantitatively, with identity being measured before and after an intervention. An outline of many quantitative measures for identity is presented in Jetten *et al.* (2012). The Bradford Dementia Group has also started developing a 'self-test', to measure changes in aspects of self and identity of people with dementia, which could also be used to determine the effectiveness of an intervention or care methods. Another possibility would be to explore any change in behaviour or attitudes of care home staff following the introduction of either an identity champion, or training on incorporating identity in daily care.

#### 7.10. Conclusions

This thesis presents a qualitative study, conducted longitudinally, across case studies of three care homes in Greater Manchester. It involved observations and semistructured interviews with residents, relatives and care home staff, with the aim to explore how the transition to a care home impacted residents' sense of identity.

Using SIP as a lens through which to interpret findings, the study highlighted the importance of independence and autonomy for residents' personal identities. The ageing process influenced residents' perceptions of their abilities and independence, but the transition to a care home had a much more significant affect. The rules and routines of the care home restricted how residents were able to exert their independence and individuality. However, many residents re-assessed how they interpreted the concept of independence to focus on their physical independence and the ability to conduct small tasks in the care home, in order to feel that they were still reflecting to this element of their identities. The study also demonstrated the psychological techniques that residents without dementia utilised in order to maintain a positive sense of self. Social comparison was the main strategy available to residents without dementia, who compared themselves with residents with dementia in terms of their cognitive and physical abilities. Re-assessing the concept of independence and physical abilities. Re-assessing the concept of independence and physical abilities.

Findings echoed other studies identified in the literature that emphasise the significance of maintaining meaningful social networks and engaging in particular activities in order to promote a positive quality of life and improve well-being. This study adds to this literature by suggesting that one reason why such issues are important are related to the continuity of self. Without interactions with relevant social groups and networks, residents were unable to reinforce their perceived identities. Consequently, they were at risk of inheriting a negative social identity. First, of being a care home resident, which is associated with frailty and dependence, concepts that directly contradicted their personal identities. Second, residents without dementia were also at risk of being considered to be 'as bad as' residents with dementia, who most participants, including staff, considered to be less of a person and represented the worst consequences of ageing.

Residents had minimal relationships with important social networks outside of the care home, and limited opportunities or motivation to forge new relationships within the care home. They therefore had a dearth of 'significant others' with whom they could engage in identity work and reinforce a positive self-concept. When opportunities arose to do so, residents without dementia chose to engage in psychological distancing and comparisons with residents with dementia, by highlighting their relative physical independence and superiority.

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Author(s) Set	tting	Participants	Methods and analysis	Additional inclusion/exclusion	Definition of identity	Findings	Themes
				criteria			
Anbäcken, Ja EM; Minemoto, K; Fujii, M. (2015)	iapan	6 female residents	Qualitative.Participant observations with 19 residents (10 days). Interviews with 6.The field notes included reports on conversations and were mainly written in English; those which were in Swedish have been translated into English when used in the article.Duration: 10 days (1 week of participant observations)Participants had dementia?: Yes	"All the interviewed residents were women, aged between their late 70s and the early 90s.13 All had a dementia diagnosis according to the Japanese scale. "	Not given	Frustration at being in facility and not being in control. Loss of independence (business) Identity is challenged. Loneliness. Participation in daily activities distinguishes them as healthy and able in comparison to the others who are "ill". Staff do some "scaffolding," supporting to perform certain actions during the course of the day. Dementia accepted as an illness without fear of losing one's mind.	<ol> <li>Frailty/illness</li> <li>Independence         <ol> <li>Roles</li> <li>Relationships</li></ol></li></ol>

# Appendix 1: Data extraction table

Cohen-	Israel	27 staff	Mixed methods	Aged over 55;	Role identity	All role identities	1. Roles.
Mansfield,	Istuet	interviews.	Structured interviews and	dementia of at least 6	itere raentry	deteriorated significantly.	2. Family.
J;		25 family member	case study.	months in duration;		Family roles retained the	3. Activities and
Golander,		interviews.	Complete interviews of	participant resides in		greatest prominence in the	hobbies
H;		26 resident	residents, formal and	the institution for at		present.	4. Imaginary
Arnheim,		interviews (76.3%	informal caregivers were	least 2 months, so that		Residents expressed sadness	identities
G. (2000)		female. 23.7%	conducted for only for 12	staff members are		over loss of roles and	
、 <i>、 、 、</i>		male).	residents.	sufficiently familiar		memories of rolls.	
				with them; and		TV watching most common	
			Assessments	participant has an		present leisure activity as	
		2 nursing homes	Four close-ended	informal caregiver		described by staff, and past	
		_	questionnaires.	who has known them		activity described by family	
			Residents, relatives, and	in the past.		members.	
			staff members interviewed			Residents said reading was	
			to provide information about			most common past activity.	
			past roles and the degree to			Staff and family members	
			which those roles are			said some residents had	
			maintained in the present,			created imaginary identities.	
			and about strategies for			Residents had imaginary	
			bolstering the sense of self-			identities based on false	
			identity.			memories.	
			Duration: Not stated				
			Participants had dementia?:				
			Yes				
Golander,	Israel	33 residents (73%	Qualitative.	None identified	Changing	Illness and ageing process	1. Frailty/
Н. (1995)		female. 27%	Ethnography. Participant		conceptions of	led to "betrayal of the body".	Illness
		male)	observations of everyday		one's self,	Social interaction among	2. Routines
		1 nursing home	institutional life.		body, and	residents characterised by	of the care
					biographic	indifference, competition and	home
			Follow-up with several key		time. They	hostility.	3. Activities and
			informants until all original		form the	Demented residents seen as a	hobbies
			residents passed away		"biographical	nuisance, and avoided.	
					body	No friendships formed.	

				1		
			Analysis: Not detail on type	conception	Limited possessions.	3. Relationships
			of analysis.	(BBC) chain".	Relationships between	with other
				Conceptions	residents, families and staff	residents
			Duration: Observations	of self-	were positive.	4. Relationships
			conducted 1984-1985	identity	New dilemma of how to	with family
				arising	reconstruct identity. "I am	members and
			Participants had dementia?:	through the	what I am, but I'm not what I	staff
			Mixed	body over	was".	
				biographical	No opportunities to learn	
				time.	new skills/hobbies.	
Heggestad,	Norway	15 residents with	Qualitative.	"Dignity of	Gymnast and a singer. By	1. Life stories
AKT;	5	dementia (no	Phenomenological and	identity" = a	telling her story, she painted	2. Roles
Slettebø,		information on	hermeneutic design.	subjective	a picture of who she had	3. Activities and
A. (2015)		gender)	C	form of	been, so that the listener	hobbies
		2 nursing homes	Case study design. 3	dignity, like	could see that she was more	
			cases/stories.	self-respect,	than just one resident among	
				and related to	others, and more than a	
			Participant observation and	autonomy,	person who suffered from	
			qualitative interviews.	integrity and	dementia related identity to	
			Formal interviews with 5	social	earlier roles	
			residents. Open-ended	relationships.	carrier roles	
			questions.	relationships.		
			questions.			
			5 residents from a special			
			care unit, and one general			
			,			
			unit in 2 nursing homes			
			(n=15).			
			Analyzia: Norrativa analyzia			
			Analysis: Narrative analysis			
			Duration: March 2010 -			
			Duration. March 2010 - December 2010			
			December 2010			
			Participants had dementia?:			
			1			
			Yes			

Moss, S;	USA	21 men	Qualitative.	Not mentioned	Hegemonic	The centrality of work: Work	1. Relationships
Moss, M.		5 long-term care	Part of a study of		masculinity.	central in maintaining their	with family
(2007)		facilities (9 in	Bereavement in Long Term		Mentioned	sense of identity.	members
		nursing homes &	Care. In-person interviews.		Charmaz	Salience of the wife: Wives	(wives)
		12 in assisted	1		(1983) our	help to ascribe meaning to	2. Relationships
		living facilities)	Analysis: "Examined using		characteristics	their lives in LTC. Notion of	with other
		0 /	standard qualitative analystic		that erode the	couplehood and	residents
			methods" - description		sense of self:	protectiveness over wives	3. Frailty/illness
			sounds like thematic		the	also important.	4. Activities and
			analysis.		restrictions of	Distancing social ties:	hobbies
					their daily	Regulate social ties with	5. Roles
			Duration: "Multi year"		lives, their	other residents.	
					sense of social	Instrumental interaction with	
			Participants had dementia?:		isolation,	other residents, using their	
			Not stated		being	work skill to help.	
					devalued, and		
					a belief that		
					they are		
					burdening		
					others.		
Oosterveld	Netherla	30 residents (18	Qualitative.	Recently admitted to a	Model of	Three domains threatened by	1. Dignity
-Vlug,	nds	women. 12 men).	"Qualitative descriptive	long-stay unit for	Dignity in	illness:	2. Illness
MG;		4 nursing homes.	methodology".	residents with physical	Illness	Individual self: Illness-	3. Decision-
Roeline, H;			In-depth interviews.	illnesses and able to		related conditions affected	making.
Pasman,			Purposefully sampled	understand the study,		personal dignity.	4. Independence
W; van			nursing homes. Sampling of	give informed consent		Activities not compensate for	5. Routines of
Gennip,			participants was aimed at	and speak		feelings of meaninglessness,	the care home
IE; Muller,			maximizing the range of	comprehensibly in		loneliness and boredom.	6. Relationships
MT;			residents' characteristics	Dutch.		Relational self: Dependent	with other
Willems,			(gender, age, cultural	Residents with severe		on others. Undermined	residents.
DL;			background, religion and	dementia were		personal dignity.	7. Appearance
Onwuteaka			type of illness). Interviewed	excluded.		Shrunken social networks.	8. Activities and
-Philipsen,			a few weeks after admission.	Excluded residents on		Other residents too ill to	hobbies
BD. (2014)			Topic list e.g. "what factors	rehabilitation wards,		connect with.	
			are important for your sense	whose length of stay is		Societal self: Looking well-	

		of dignity?" Analysis: Thematic analysis. Duration: May 2010–June 2011 Participants had dementia?: No	often short.		groomed important to maintain dignity (women). Living in a NH made them more aware that they were no longer part of society. Felt stigmatised by society. Not taken seriously because of age or illness.	
Riedl, M; Austria Mantovan, F; Them, C. (2013)	a 20 residents across 3 nursing homes (15 women, 5 men)	Qualitative. 20 problem- orientated interviews. Data saturation. Interview guidelines based on literature research on identity theory of Petzold. Semi-structured guidelines divided into questions on current life situation, review of the past, change of identity caused by moving away from home and into a nursing home, social contacts in the nursing home, and questions on expectations and wishes for the future. Tested on a female nursing home resident. Modified accordingly Analysis: Content analysis (Mayring). Duration: July-August 2010 Participants had dementia?: No	Stayed in a nursing home less than one year. Over 70 years old. Mental stability. Not bed-ridden. Cognitive ability to answer questions. Competence to process information on research subject. No diagnosis of dementia.	Identity Theory of Petzold. Identity is the result of ego's synthesis performance in the processing of reciprocal identifications from diverse contexts, their emotional evaluation, the cognitive assessment, and their connection with identifications . The answers to the questions "who am I?" and" who do I	Feel left alone. Conditions of the fellow residents creates a strain. Loss of work provokes feelings of being nothing. Some prayed. Participants often downplayed offers made by nurses to support them due to physical deficits. Compared normality in the nursing home with their life situation at home, prior to the transition. Try to keep as many of their habits as possible. Kept objects from when younger. Want to partake in actives that are comparable to their previous hobbies and roles. Conflicts amongst residents. Longing for death.	<ol> <li>Physical ability</li> <li>Activities and hobbies</li> <li>Roles</li> <li>Relationships with other residents</li> <li>Possessions</li> <li>Appearance</li> </ol>

					belong to?"		
Surr, C.	England	14 people with	Qualitative.	Criterion sampling	Socio-	Findings support the	1. Relationships
(2006)	and	dementia (13	3-8 unstructured interviews	approach on the basis	biographical	relevance of a socio-	with family,
	Wales	female. 1 man)	per participant.	of participating in the	theory of	biographical theory of self.	2. Relationships
		across	Biographical data relating to	well-being study for a	selfReferen	Relationships with family,	with other
		4 residential	areas such as health,	minimum of 6 months,	ces symbolic	other residents and care	residents
		homes.	medication, activities of	consenting to having a	interactionism	home staff were important	3. Relationships
			daily living, occupation,	minimum of 3	, including	for maintenance of self.	with staff.
			levels of well-being,	unstructured	Sabat and	Social roles (work, family,	2. Roles (work
			spiritual well-being, social	interviews tape-	Harre/Sabat	caring for others/being cared	and family)
			relationships, and	recorded over this	and Collins.	for). Some adopt roles within	3. Life stories
			communication abilities	period, and being		care home.	
			were also collected from	verbally articulate		Creating life stories of	
			staff and home records.	enough to create		selected events important for	
				narratives and tell		maintenance of self.	
			Analysis: Interpretive	stories.		Loss of contact with family	
			biographical methodology.			and social roles.	
			Involved (1) creation of a	The five most recent		For some, relationships with	
			biography, (2) thematic	admissions to the		other residents gave them a	
			textual analysis, (3)	home or wing, who		feeling of being included.	
			construction of a 'story' of	had an MMSE of 20		Positive relationships with	
			self, (4) micro-analysis of	or less.		staff promoted self.	
			the text in light of the			The social context had	
			biography and (5)			limited affect on self,	
			comparison of the stories of			because they had little	
			self.			contact with the social world	
						and community.	
			Duration: 6-24 months.				
			visited on a three-monthly				
			basis over a 2-year period.				
			Participants had dementia?:				
			Yes				

Tester, S;	Scotland	52 residents (no	6 focus groups in the	Moved to care home	Not given.	Four key aspects of life	1. Frailty
Hubbard,	Scotland	information on	community	in previous 6 months	i tot given.	perceived as components of	3. Possessions
G.; Downs,		gender)	community	in previous o montins		quality of life:	and appearance
M.;		gender)	Naturalistic observations in			Sense of self; The care	5. Relationships.
Macdonald			4 care homes (2 hours at a			environment; Relationships;	6. Routines of
, C;			time during the day, longer			Activities. All inter-related.	the care home
, C, Murphy, J.			at night; each day of the			Express their sense of self	7. Independence
(2004)			week).			through feeling 'at home' in	8. Activities and
(2004)			week).			the home.	hobbies
			Observations and interviews			Express identity through	9. Relationships
			with 52 residents.			appearance and possessions	with other
			with 52 residents.			Frailer residents had less	residents.
			10 residents used			control, choice and privacy.	residents.
			TalkingMats as a visual			Quality of life was inhibited	
			framework.			if they did not feel at home	
			inume work.			or could not express their	
			Duration: 2 hours at a time			sense of self.	
			during the day and a longer			Having control as was	
			period at night, covering			important to maintain a sense	
			each day of the week and			of self.	
			over 24 hours			Acceptance of the need to fit	
						in with rules/regulations, but	
			Participants had dementia?:			with a sense of loss of	
			Yes ("most had a diagnosis			freedom.	
			of dementia")			Meaningful interaction	
			,			essential for sense of self.	
						Loss of familiar company.	
						Range of feelings towards	
						other residents.	
						Some residents felt the daily	
						routine was as much as they	
						wanted to cope with. Others	
						were bored and frustrated.	
						Rarely left the care home.	
Welsh, D;	Canada	Eleven residents,	Qualitative. In-depth,	Mini-Mental State	not given	Four themes:	1. Frailty/illness

Moore, SL;	7 men and 4	audiorecorded, semi-	Examination (MMSE,		Connectedness:	2. Activities and
Getzla,	women	structured interviews were	Folstein, Folstein, &	F	Relationships help establish	hobbies
BA. (2012)		conducted to obtain	McHugh, 1975) scores		sense of self or identity.	
		experiential descriptions.	of 20 or greater and		Family, friends and	
			deemed cognitively	c	caregivers are central to life	
		Duration: Not stated	able to participate;		world, experience of	
			able to and interested		connectedness and finding	
		Participants had dementia?:	in describing their		meaning.	
		No	experiences of		Admission to LTC fades	
			meaning in life; and		connectedness.	
			able to provide		Reminiscing about family	
			informed consent.		provided continuity with	
					identity.	
					Survival despite declining	
					functional capacity:	
					Self can be compromised	
					when activities of daily	
				1	iving cannot be performed.	
					Helplessness and loss of	
					autonomy.	
					Engaging in 'normal'	
					activities:	
				Re	esidents adapted to changes	
					by continuing in activities	
					that were considered a	
					normal part of life prior to	
					relocation.	
					Sense of self derived from	
					these activities.	
					Seeking a place of refuge:	
					Continued to strive for	
					autonomy and privacy via	
					integration of past lived	
					space in to present.	

## Appendix 2: CASP tool

# 1) Anbäcken *et al.* (2015)

1) Anbäcken <i>et al.</i> (2015)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?			5
2. Is a qualitative methodology appropriate?	1		
3. Was the research design appropriate to address the aims of the research?		1	
4. Was the recruitment strategy appropriate to the Yes aims of the research?		1	
5. Was the data collected in a way that addressed the research issue?		1	
6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?	1		
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?			1
10. How valuable is the research?	1		
2) Cohen-Mansfield et al. (2000)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?	✓		
2. Is a qualitative methodology appropriate?	1		
3. Was the research design appropriate to address the aims of the research?	1		
4. Was the recruitment strategy appropriate to the Yes aims of the research?	1		
5. Was the data collected in a way that addressed the research issue?	1		

6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?			1
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		
3) Golander (1995)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?			1
2. Is a qualitative methodology appropriate?	1		
3. Was the research design appropriate to address the aims of the research?		1	
4. Was the recruitment strategy appropriate to the Yes aims of the research?		1	
5. Was the data collected in a way that addressed the research issue?		1	
6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?			1
8. Was the data analysis sufficiently rigorous?			1
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		
4) Heggestad and Slettbø (2015)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?	1		
2. Is a qualitative methodology appropriate?	1		
	-		1

3. Was the research design appropriate to address the aims of the research?	1		
4. Was the recruitment strategy appropriate to the Yes aims of the research?	1		
5. Was the data collected in a way that addressed the research issue?	1		
6. Has the relationship between researcher and participants been adequately considered?	1		
7. Have ethical issues been taken into consideration?	1		
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?			1
10. How valuable is the research?	$\checkmark$		
5) Moss and Moss (2007)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?	1		
	•		
2. Is a qualitative methodology appropriate?	✓ ✓		
<ul><li>2. Is a qualitative methodology appropriate?</li><li>3. Was the research design appropriate to address</li></ul>	1		
<ul><li>2. Is a qualitative methodology appropriate?</li><li>3. Was the research design appropriate to address the aims of the research?</li><li>4. Was the recruitment strategy appropriate to the</li></ul>	1		
<ol> <li>Is a qualitative methodology appropriate?</li> <li>Was the research design appropriate to address the aims of the research?</li> <li>Was the recruitment strategy appropriate to the Yes aims of the research?</li> <li>Was the data collected in a way that addressed</li> </ol>	J           J           J		
<ol> <li>Is a qualitative methodology appropriate?</li> <li>Is a qualitative methodology appropriate?</li> <li>Was the research design appropriate to address the aims of the research?</li> <li>Was the recruitment strategy appropriate to the Yes aims of the research?</li> <li>Was the data collected in a way that addressed the research issue?</li> <li>Has the relationship between researcher and</li> </ol>	J           J           J           J           J		
<ol> <li>Is a qualitative methodology appropriate?</li> <li>Was the research design appropriate to address the aims of the research?</li> <li>Was the recruitment strategy appropriate to the Yes aims of the research?</li> <li>Was the data collected in a way that addressed the research issue?</li> <li>Has the relationship between researcher and participants been adequately considered?</li> <li>Have ethical issues been taken into</li> </ol>	J           J           J           J           J		
<ul> <li>2. Is a qualitative methodology appropriate?</li> <li>3. Was the research design appropriate to address the aims of the research?</li> <li>4. Was the recruitment strategy appropriate to the Yes aims of the research?</li> <li>5. Was the data collected in a way that addressed the research issue?</li> <li>6. Has the relationship between researcher and participants been adequately considered?</li> <li>7. Have ethical issues been taken into consideration?</li> </ul>	J           J           J           J           J		

<ol> <li>Was there a clear statement of the aims of the research?</li> <li>Is a qualitative methodology appropriate?</li> <li>Was the research design appropriate to address the aims of the meanwh?</li> </ol>	Yes ✓ ✓	Can't tell	No
<ul><li>research?</li><li>2. Is a qualitative methodology appropriate?</li><li>3. Was the research design appropriate to address</li></ul>			
3. Was the research design appropriate to address	1		
the aims of the research?	1		
4. Was the recruitment strategy appropriate to the Yes aims of the research?	1		
5. Was the data collected in a way that addressed the research issue?	1		
6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?	1		
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		
7) Reidl and Gough (2000)			
, ,	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?	1		
2. Is a qualitative methodology appropriate?	1		
3. Was the research design appropriate to address the aims of the research?			1
4. Was the recruitment strategy appropriate to the Yes aims of the research?		1	
5. Was the data collected in a way that addressed the research issue?	1		

6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?	1		
8. Was the data analysis sufficiently rigorous?		1	
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		
8) Surr (2006)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?	1		
2. Is a qualitative methodology appropriate?	1		
3. Was the research design appropriate to address the aims of the research?	1		
4. Was the recruitment strategy appropriate to the Yes aims of the research?	1		
5. Was the data collected in a way that addressed the research issue?	1		
6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?			1
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		
9) Tester <i>et al</i> (2004)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?			1
2. Is a qualitative methodology appropriate?	1		

3. Was the research design appropriate to address the aims of the research?	1		
4. Was the recruitment strategy appropriate to the aims of the research?		1	
5. Was the data collected in a way that addressed the research issue?	1		
6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?	1		
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		
10) Welsh <i>et al.</i> (2012)			
	Yes	Can't tell	No
1. Was there a clear statement of the aims of the research?			1
2. Is a qualitative methodology appropriate?	1		
3. Was the research design appropriate to address the aims of the research?	~		
4. Was the recruitment strategy appropriate to the Yes aims of the research?	1		
5. Was the data collected in a way that addressed the research issue?	1		
6. Has the relationship between researcher and participants been adequately considered?			1
7. Have ethical issues been taken into consideration?	~		
8. Was the data analysis sufficiently rigorous?	1		
9. Is there a clear statement of findings?	1		
10. How valuable is the research?	1		



#### **NRES Committee East Midlands - Northampton**

The Old Chapel Royal Standard Place Nottingham NG1 6FS

Telephone: 0115 8839425 Facsimile: 0115 8839294

11 January 2013

Miss Katie Paddock School of Nursing, Midwifery & Social Work University of Manchester, Jean McFarlane Building University Place, Oxford Road, Manchester M13 9PL

Dear Miss Paddock,

Study title:

REC reference: IRAS project ID: The impact of the transition to a care home on older peoples' perceived identity and mental health 12/EM/0431 108618

Thank you for your letter of, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Jessica Parfrement, NRESCommittee.EastMidlands-Northampton@nhs.net.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

A Research Ethics Committee established by the Health Research Authority

#### NHS sites

The favourable opinion applies to all NHS sites 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).

Non-NHS sites

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the</u> <u>start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <u>http://www.rdforum.nhs.uk</u>.

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 approvals from host organisations

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).

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Daté .
Covering Letter		
Evidence of insurance or indemnity		11 June 2012
Evidence of insurance or indemnity		11 June 2012
Interview Schedules/Topic Guides	Residents 1	23 October 2012
Interview Schedules/Topic Guides	Significant other 1	23 October 2012
Interview Schedules/Topic Guides	staff 1	23 October 2012
Investigator CV		· ·   · · · · · · · · · · · · · · · ·
Letter from Sponsor		30 October 2012
Letter from Sponsor		22 October 2012

Other: CV - Professor Todd		
Other: CV - Dr Walshe		
Other: CV - Dr Wilson		30 October 2012
Other: Letter to care homes	1	23 October 2012
Other: Letter from funder		26 May 2011
Other: Protocol flow chart	1	23 October 2012
Other: Geriatric Depression Scale (15-item)	1	
Other: Recruitment poster	1	23 October 2012
Other: Distress Protocol	1	23 October 2012
Other: Focus group ground rules	1	23 October 2012
Other: Inclusion and Exclusion Criteria	1	20 December 2012
Other: Disclosure Protocol	1	20 December 2012
Other: Observation opt-out form	1	20 December 2012
Participant Consent Form: Loss of capacity	1	23 October 2012
Participant Consent Form: Staff	2	20 December 2012
Participant Consent Form: Residents		
Participant Consent Form	2	20 December 2012
Participant Information Sheet: Newly admitted residents	1	23 October 2012
Participant Information Sheet: Care home staff	2	20 December 2012
Participant Information Sheet: Significant others	2	20 December 2012
Participant Information Sheet: Care home residents	2	20 December 2012
Protocol	1	23 October 2012
REC application	108618/380512/1/808	29 October 2012
Response to Request for Further Information		

### Statement of compliance

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

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### 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 NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

### 12/EM/0431 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <u>http://www.hra.nhs.uk/hra-training/</u>

With the Committee's best wishes for the success of this project.

Yours sincerely

J. Panhement P

Mr John Aldridge Chair

Email:NRESCommittee.EastMidlands-Northampton@nhs.net

*Enclosures:* "After ethical review – guidance for researchers"

Copy to:

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Sponsor - Mrs Catherine Barrow

### Appendix 4: Confirmation of approval from NHS R&D







NHS SalfoR+D Director: R&D Associate Director: Professor Bill Ollier Rachel Georgiou

SalfoR+D web address: ReGrouP web address: http://www.nhssalfordrd.org.uk/ http://www.gmregroup.nhs.uk/index.html

26th March 2013

Miss Katie Paddock PhD student School of Nursing, Midwifery and Social Work University of Manchester, 3rd Floor Postgraduate room, Jean McFarlane Building University Place, Oxford Road, Manchester M13 9PL

Dear Katie.

#### Study Title: The impact of the transition to a care home on older peoples' perceived identity and mental health REC Reference: 12/EM/0431 R&D Reference: 2013/041

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS SalfoR+D and has gained NHS R&D approval from the following NHS Trusts:

Manchester PCT

All clinical research must comply with the Health and Safety at Work Act, www.hse.gov.uk and the Data Protection Act. http://www.hmso.gov.uk/acts

It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The 'Research Passport Application Form'. This can be obtained from web addresses:

http://www.gmregroup.nhs.uk/researchers/passports.html and http://www.hope-

academic.org.uk/academic/salfordrd/Research%20Passports.html This form should be completed and returned, with a summary C.V and recent (within 6 months) CRB to the address shown above.

It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study. <u>http://www.nres.npsa.nhs.uk/applications/after-</u> ethical-review/annual-progress-reports/ Where clinical trials of investigational medicinal products are sponsored by Salford Royal NHS Foundation Trust or Salford Primary Care Trust, it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate time) to R&D. For clinical trials of investigational medicinal products hosted within Salford Royal NHS Foundation Trust and Salford Primary Care Trust, the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor's Representative during routine monitoring of the trial. <u>Persistent non-compliance with these</u> requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study should also be notified and approval sought by Ethics Committee and R&D Department. Where Salford Royal NHS Foundation Trust or Salford Primary Care Trust is acting as Sponsor then amendments or changes MUST be discussed with the Sponsor prior to REC submission. On completion of the study you are required to submit a 'Declaration of End of Study' form to the main REC, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

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Sue Gowland R&D Manager

## Appendix 5: Letter of introduction to care home managers



Dear [care home manager],

We are writing to invite care homes in Greater Manchester to take part in a research study examining the experience of transition as older people move into residential care, and how this relates to their mental health and their sense of identity.

Previous studies have suggested that the transition to residential care has a significant impact on residents' identities, but there is no UK-based research to explore this phenomenon, nor on how this affects their mental health. Insight into how residents, their families, and care home staff perceive the transition process can inform improvements to current services, and highlight areas where care homes are performing well.

The study (described more fully in the attached information sheet) is designed to minimise the disruption to your care home staff and residents. It comprises observations and interviews with older people, and if possible, their family members or friends, and staff at your establishment. It has been approved by a REC and the ethics committee at The University of Manchester.

We would greatly appreciate the opportunity to come and talk with you about this study and answer any questions before you make any decision as to whether [name of care home] would wish to be involved.

Yours Faithfully,

**Appendix 6: Disclosure protocol** 



## **Disclosure Protocol**

Participant information sheets state that if participants say something that suggests that they or others are at risk of harm, or they score highly on the Geriatric Depression Scale, then the researcher will contact his or her keyworker or a member of staff at the care home.

Note: The relevant member of staff\* will be discussed and agreed upon at each care home. It may be the care home manager, but this can differ between homes and change if the agreed member of staff is unavailable. Participants will be informed of who that member of staff is before data collection begins.

1. The maintenance of participant confidentiality must be preserved (e.g. if participants or non-participants ask for information about other participants, this information should be refused). This also includes all staff, who will not be informed of individual participants' responses other than in the event that they are at risk of harm (see item 4).

2. If a participant scores 5 or more on the Geriatric Depression Scale, the researcher will inform his or her keyworker of a possible diagnosis of depression. If it is not possible to speak to a keyworker, then a relevant member of staff\* at the care home will be approached. The researcher will recommend that the participant speak to his or her GP. Before data collection begins, the participant will be made aware that the researcher will take this course of action and pass on his or her score on the Geriatric Depression Scale.

3. If a participant discloses sensitive information, it is appropriate to ask whether the individual has sought support.

4. If a participant discloses information that implies that they, or another person(s), are at risk of harm, the researcher will inform his or her

keyworker. If this is not possible, then a relevant member of staff at the care home will be approached. The participant will be made aware that the researcher will take this course of action before they consent to participate.

5. Should a participant indicate that they are being abused in the care home, or if the researcher witnesses abuse, the following steps will be taken:-

a. To make a formal complaint about the care home, the researcher will contact the Care Quality Commission, which regulates care homes. This will be done either via email or the helpline.

b. If the researcher witnesses physical abuse or other criminal activity in the care home, she will contact the police immediately.

## Appendix 7: Distress protocol

Distress protocol Version 1: 23/10/12



## **DISTRESS PROTOCOL**

# Exploration of multiple perspectives on the impact of relocation to an elderly care home on residents' sense of identity and depressive symptoms

This distress protocol is to be used in interview and focus group situations to monitor participants' experience of distress and guide the response to this distress.

- a) Indications of distress during the interview. Researcher should be aware of and alert for indications of a high level of stress or emotional distress OR the exhibiting of behaviours suggestive that the interview is too stressful such as uncontrolled crying, incoherent speech, indications of flashbacks etc. If distress is detected:
  - Stop the interview
  - Offer support and allow the participant time to regroup
  - Assess mental status (Tell me what thoughts you are having, what are you feeling right now, do you feel able to go on with the rest of the day, do you feel safe?)
  - Determine if the person is experiencing acute emotional distress beyond what would be normally expected in an interview about a sensitive topic. If detected, stop the interview completely.
- b) If distress is reflective of what may be expected in an interview about a sensitive topic offer support and extend the opportunity to i) stop the interview completely, or ii) stop and regroup and then make decision to stop, or iii) stop, regroup and continue.
- c) If distress of any level is detected, at either stop point (as above) or end of interview (if continued) take the following actions:
  - Encourage participant to contact their regular health provider (staff member, GP, nurse, consultant for example) for follow up.

- Provide the participant with details of local support groups and services they may wish to access.
- Indicate that, with permission, you will contact them the following day to see if they are okay.
- d) If severe or acute emotional distress was detected or continues after the interview has stopped, in addition to point c) above:
  - Request permission from participant for you to contact their regular health provider. OR
  - If there are any concerns about their immediate safety contact their regular health provider without their permission or dial 999 for assistance.

**Appendix 8: Participant information sheet for care home residents** 



School of Nursing, Midwifery & Social Work University of Manchester Jean McFarlane Building, University Place, Oxford Road, Manchester, M13 9PL

# Participant information sheet for care home residents

<u>Study title:</u> Transition to a care home: Identity and mental health in older people

We are inviting you to take part in our research study from the University of Manchester. The researcher for this study is Katie Paddock.

Before you decide whether to take part, we would like you to understand why the research is being done and what it would involve for you. A member of staff at the care home or a research nurse can go through this information sheet with you. If you have any questions, care home staff or a research nurse will contact Katie, who will answer any questions you have. Talk to others about the study if you wish.

Once you have been given information about the study,

and are satisfied that you understand what is being asked, you will have a week to decide whether you would like to be included in the study. If you would like to be involved, a research nurse will pass on your details to Katie, who will arrange a time to meet with you. Katie's contact details are below.

This study is voluntary and you do not have to take part.

# Part 1: About the study

## What is the purpose of the study?

This study aims to explore your move to the care home, and how it made you think and feel about yourself. We understand that moving to a care home can be difficult for some people, but studies do not ask residents what *they* think about relocating.

We want to know about you and your 'identity': what you were like when you were younger, the things you enjoyed doing, and how this has changed over time. We would also like to discuss how these things have changed since you have moved to the care home, and how you are getting on since moving here.

Overall, the whole study will take about two years to complete, analyse, and write-up. You can drop out at any time.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Northampton Research Ethics Committee.

## Who else has been invited?

This study will involve some of your family and/or friends, if they would like to take part. Other residents and their friends/families will be asked to take part.

As the aim of the study is to explore your move here, your friends/family and staff members will be asked questions about you, and how they feel the move went for you.

## What will you have to do?

If you agree to take part, Katie will interview you one-onone. This will be in a private room and interviews should last about an hour, or less if you want to stop earlier. I would like to interview you about once a month, but this is negotiable.

Katie will visit and **participate** in the life of the home by speaking with you and other residents during the day. This will help to understand how you spend your day following the move. You do not have to be involved in this and Katie will check with you each time she visits. You can opt out of these observations. Anyone who does not wish to be included in the observations should inform the researcher or a member of staff and their information will not be included.

It should be stressed that these interviews are not a form of counselling. If you share with me emotional issues that I think needs to be shared with a member of staff, I will inform you so that you can be supported after I leave.

You will be asked to complete a short **questionnaire** called the Geriatric Depression Scale. These are 15 quick

yes/no questions that aim to identify symptoms of depression. We will ask you to fill this in about once a month to see whether your answers change over time.

You may also be asked to take part in a **focus group**, where other residents and friends/relatives in the care home will discuss your experiences with the researcher. You do not have to take part in a focus group if you do not wish to do so. This should take about an hour.

# What will happen to the information you share?

Interviews and focus groups will be audio recorded and then transcribed word-for-word so the researcher can analyse the results at the end of the study. All information will be made anonymous, so your name will not be included.

Information from interviews and focus groups will be kept confidential. We will not tell anyone else what you have said. If you say something very interesting then we will discuss that issue with other participants, but we will not say that it was you who had said it. This will keep your information confidential, but also provide interesting talking points for other interviews and focus groups.

You can read through your transcribed information to see what you have said, to give you the opportunity to add or change anything.

At the end of the study, all the information will be analysed to see whether there are similarities or differences in participants' responses. Then, the study and results will be written up in a report as part of a PhD at the University of Manchester. After that, it will be submitted for publication in a journal.

Participants, and the care home, will be given a report of the results found in that care home.

## What are are the benefits?

## **Advantages**

You will get to be a part of an informative study that aims to improve care for care home residents.

You will also have the opportunity to talk about your experiences and raise any good or bad points about your move and life in a care home, with the comfort of your information being kept confidential.

The focus groups will give you the opportunity to talk to other residents and share your story with people who may have had similar experiences.

## What might be some of the disadvantages?

If discussions in the interviews and focus groups turn to sensitive topics, you may become upset. The researcher will arrange for someone to talk to you after the interview.

# Part 2

What if you have a problem or want to make a complaint?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. If the researcher is at your care home on the day, you can ask to talk to her in private to discuss any problems. If she is not available in person, you can get in touch with her or her supervisors via the contact details below.

Should you wish to complain formally, you can do this without any negative consequences. To complain, you can contact the supervisors below. To speak to someone who is not associated with the study, contact Lynne Macrae, whose details are also below.

# What if you don't want to take part anymore?

You can withdraw from the study at any time, but we will use the information collected up to your withdrawal.

Alternatively, if you do not feel like being interviewed for a little while, but would still like to be part of the study, you can re-arrange another date to be interviewed.

## Will your information be kept confidential?

The information we collect will be kept confidential – though we cannot assure that other participants in the focus group will maintain confidentiality.

If you raise a particularly interesting point, we will include it in other interviews and focus groups, but will not say that it was you who said it. However, if you say something that suggests risk to yourself or someone else, we will have to speak to a member of staff at the care home or your keyworker. This is to ensure your safety, and the safety of others.

## **Contact information**

If you have any further questions do not hesitate to contact us at the University of Manchester:

**Researcher:** Katie Paddock School of Nursing, Midwifery & Social Work University of Manchester, 07790 251561

**Supervisor:** Prof. Chris Todd, School of Nursing, Midwifery & Social Work University of Manchester, 0161 306 7865

**Supervisor:** Dr Catherine Walshe, School of Nursing, Midwifery & Social Work University of Manchester, 0161 306 7649

Ms Lynne Macrae, Research Practice Coordinator, 0161 275 5436, Email: <u>lynne.macrae@manchester.ac.uk</u> **Appendix 9: Participant information sheet for significant others** 



# Participant information sheet for significant others

# Study Title: Transition to a care home: Identity and mental health in older people

We would like to invite you to take part in our research study from the University of Manchester. The researcher for this study is Katie Paddock.

Before you decide whether to take part, we would like you to understand why the research is being done and what it would involve for you. A member of staff at the care home or a research nurse can go through this information sheet with you. If you have any questions, care home staff or a research nurse will contact Katie, who will answer any questions you have. Talk to others about the study if you wish.

Once you have been given information about the study and are satisfied that you understand what is being asked, you will have a week to decide whether you would like to be included in the study. If you would like to be involved, a research nurse will pass on your details to Katie, who will arrange a time to meet with you. Katie's contact details are below.

This study is voluntary and you do not have to take part.

# Part 1: About the study

## What is the purpose of the study?

This study aims to explore care home residents' move to the care home, and how it made them think and feel about themselves. We understand that moving to a care home can be difficult for some people, but there are not many studies that ask residents how they thought about relocating.

We would like to know about their 'identity': what they were like when they were younger, the things they enjoyed doing, and how this has changed over time. We would also like to discuss how these things have changed since he/she have moved to the care home, and how they are getting on since moving here.

Overall, the whole study will take about two years to complete, analyse, and write-up. You can drop out at any time.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Northampton Research Ethics Committee.

## Who else has been invited?

This study will also involve the resident to whom you are close or related. As the aim of the study is to explore residents' experiences of the move to a care home, the resident will be asked questions about how the relocation process impacted their sense of identity.

As the aim of the study is to explore your move here, the resident at the care home and staff members will be asked to share their opinions on how they feel the move went for your friend/family member.

## What will you have to do?

If you agree to take part, Katie will interview you one-onone. This will be in a private room and interviews should last about an hour, or less if you want to stop earlier. I would like to interview you once a month, but this is negotiable. Interviews will be audio recorded to help with analysis.

Katie will visit and **participate** in the life of the home by speaking with you, residents and other visitors during the day. This will help to understand how residents spend their days following the move. You do not have to be involved in this and Katie will check with you each time she visits. You can opt out of these observations. Anyone who does not wish to be included in the observations should inform Katie or a member of staff, and their information will not be included.

If you later decide that you wish to have your information removed from an observation, you can complete an 'observation opt-out' form. You ask Katie or a member of staff for one. Once completed and submitted to Katie, your information will not be included in the study for that observation.

It should be stressed that these interviews are not a form of counselling. If you share with Katie some emotional issues that she thinks needs to be shared with a member of staff, she will inform you so that you can be supported after she leaves.

You may also be asked to take part in a **focus group**, where residents and other friends/relatives in the care home will discuss your experiences with Katie. This should take about an hour. You do not have to take part in a focus group if you do not wish to do so.

# What will happen to the information you share?

Interviews and focus groups will be audio recorded and then transcribed word-for-word so Katie can analyse the results at the end of the study. All information will be made anonymous, so your name will not be included.

Information will be kept confidential. We will not tell anyone else what you have said. If you say something very interesting then we will discuss that issue with other participants, but we will not say that it was you who had said it. This will keep your information confidential, but also provide interesting talking points for other interviews and focus groups.

You can read through your transcribed information to see

what you have said, to give you the opportunity to add or change anything.

At the end of the study, all the information will be analysed to see whether there are similarities or differences between what participants have said. Then, the study and results will be written up in a report as part of a PhD at the University of Manchester. After that, it will be submitted for publication in a journal.

Participants, and the care home, will be given a report of the results found in that care home.

## What are the benefits?

## **Advantages**

You will have the opportunity to talk about your experiences and raise any good or bad points about the move, with the comfort of your information being kept confidential.

You will get to be a part of an informative study that aims to improve care for care home residents.

The focus groups will give you the opportunity to talk to others and share your story with people who may have had similar experiences.

## What might be some disadvantages?

If discussions in the interviews and focus groups turn to sensitive topics, you may become upset. The researcher will arrange for someone to talk to you after the interviews if you do.

# Part 2

# What if you have a problem or want to make a complaint?

If you have a concern about any aspect of this study, you should ask to speak to Katie who will do her best to answer your questions. If Katie is at the care home on the day, you can ask to talk to her in private to discuss any problems. If she is not available in person, you can get in touch with her or her supervisors via the contact details below.

Should you wish to complain formally, you can do this without repercussions. To complain, you can contact the supervisors below. To speak to someone who is not associated with the study, contact Lynne Macrae, whose details are also below.

# What if you don't want to take part anymore?

You can withdraw from the study at any time, but we will need to use the information collected up to your withdrawal.

Alternatively, if you do not feel like being interviewed for a little while, but would still like to be part of the study, you can re-arrange another date to be interviewed.

## Will your information be kept confidential?

Katie will keep all the information collected confidential.

If you raise a particularly interesting point, we will include it

in other interviews and focus groups, but will not indicate that it was you who said it.

However, if you say something that suggests risk to yourself or someone else, Katie will have to speak to a member of staff at the care home or your GP. This is to ensure your safety, and the safety of others.

# **Contact information**

If you have any further questions do not hesitate to contact us at the University of Manchester:

**Researcher:** Katie Paddock School of Nursing, Midwifery & Social Work University of Manchester, 07790 251561

**Supervisor:** Prof. Chris Todd, School of Nursing, Midwifery & Social Work University of Manchester, 0161 306 7865

**Supervisor:** Dr Catherine Walshe, School of Nursing, Midwifery & Social Work University of Manchester, 0161 306 7649

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk Appendix 10: Participant information sheet for care home staff



School of Nursing, Midwifery & Social Work University of Manchester Jean McFarlane Building, University Place, Oxford Road, Manchester, M13 9PL

# Information Sheet for care home staff

# <u>Study title:</u> Transition to a care home: Identity and mental health in older people

You are invited to take part in research that is being run by the University of Manchester. The researcher for this study is Katie Paddock. Below is brief summary of the aims.

The purpose of the study is to examine older peoples' experience as they move to residential care, and how this impacts their sense of identity and mental health. The move to a care home is often a difficult time for older people and their families, but there is a gap in the research that this study aims to address. It is important to include the opinions of residents, significant others (e.g. relatives, friends, carers), and staff members in order to achieve a better understanding of the move to a care home for all concerned.

# **Background and aims**

Studies have identified an increase in depressive symptoms in older people following admission to a care home, but it is often unrecognised and under-diagnosed. Depression can be harmful if left untreated and has a very negative impact on quality of life.

Some studies also suggest that moving to a care home threatens an individual's identity. For instance, if an older person is unable to take part in a meaningful activity (e.g. gardening) due to admission to residential care or physical impairments, this may influence how that individual thinks of him/herself as a person.

However, few studies have attempted to examine these issues in the context of a care home. Including the perspectives of residents, significant others, and care home staff can help to determine how experiences could be improved for all concerned, or what care homes are doing well to support older people throughout this emotive time.

This study has been reviewed and approved by the Northampton Research Ethics Committee, and the University of Manchester Ethics Committee.

# **Methods**

Katie, or a research nurse, will liaise with care homes to discuss participation in the study. Overall, the whole study will take about two years to complete, analyse, and writeup. Participants can drop out at any time.

Care home staff will be supplied with a table of inclusion and exclusion criteria for participants. Staff or research nurses will discuss the research with potential participants who meet the inclusion criteria, and distribute the relevant information sheets. Potential participants will have a week to decide whether they would like to be included in the study. If potential participants have any questions or concerns, a research nurse or member of staff can forward their details to Katie, who will contact that participant and answer their questions. If participants wish to take part, Katie will meet with them to complete a consent form.

Katie will visit and **participate** in the life of the home by speaking with residents and others during the day. This will help to understand how residents spend their day following the move. Participants can opt out of these observations. Anyone who does not wish to be included in the observations should inform the researcher or a member of staff and their information will not be included.

If anyone wishes to have their information removed from field notes and transcripts after the observation has taken place, they can have an 'Observation Opt-Out' forms. These forms can be obtained from the researcher or a member of staff. Once completed and submitted to the researcher, that person's information will not be included in the study for that observation.

Residents will be **interviewed** one-on-one by Katie about their move to the care home, with a focus on how the move made them feel and think about themselves, or how they think others see them. Participants will be interviewed at approximately a monthly basis to explore how this has changed over time. Significant others and members of staff will also be asked to include their thoughts on the issue, and on the transition process in general. Interviews will be audio recorded to help with analysis.

Additionally, residents will be asked to complete a 15-item questionnaire called the **Geriatric Depression Scale (GDS)** on a monthly basis, to examine any changes in depressive over time. As the GDS was not designed for use in care homes, the results from these interviews may be used to inform the construction of a version of the GDS for care homes.

Katie has a counselling qualification and experience conducting qualitative research on sensitive topics, and with vulnerable adults. She can detect discomfort in participants and will postpone data collection if participants become distressed.

If participants wish to be interviewed in a private area, Katie will liaise with care homes in advance to arrange for a room to be available.

Participants may also be asked to take part in a **focus group**, where other residents and friends/relatives in the care home will discuss your experiences with Katie. You do not have to take part in a focus group if you do not wish to do so. This should take about an hour.

# **Benefits of the study**

This study will give all those involved the opportunity to share their experiences and opinions on an important issue in health care that has previously been neglected. Following completion of the study, Katie will submit a report to the University of Manchester as part of a PhD degree, with an aim for publication at a later date.

Katie will also construct an individual report for each care home, highlighting the main issues that arise. This report may be useful for care homes to learn more about the positive and negative experiences of transitions.

Katie will also regularly liaise with nursing staff. She will be happy for staff to shadow her throughout the study, where appropriate, in order to get a better understanding of the research process.

# Safeguarding

### Participation and consent

Residents with severe cognitive and/or communicative impairment will be excluded from the study. Residents may develop cognitive impairments (e.g. dementia) over the course of data collection, but will be asked to remain in the study. This will be done on an individual basis.

People with dementia can still give consent, but have been excluded from many studies and thus not given the opportunity to give their opinions. Katie will regularly discuss involvement in the study with all participants before collecting data, to ensure they wish to remain in the study. Participants can choose to leave the study, or ask to be spoken to at another time.

Katie and a research nurse will regularly liaise with care home staff to discuss the eligibility of residents to participate, as staff will know who will have the capacity to give informed consent, can understand the aims of the research and what participation in the research would involve.

## Confidentiality

Names of participants and care homes will be made anonymous so that they are not identifiable in any transcripts or reports. Katie will give participants copies of their own transcripts to check that their opinions have been accurately recorded and if there is anything they wish to add or remove.

Participants' responses will be kept confidential unless they disclose information to the researcher that indicates the participant or another individual is at risk of harm. Participants who score highly on the Geriatric Depression Scale are also at risk of developing depression. If either event arises, Katie will either contact the resident's keyworker, or a pre-arranged member of staff, who will be informed of any safeguarding concerns. Participants will be made aware of these arrangements before they consent to participate.

The distress and disclosure protocols will be provided to you with this information sheet.

# **Complaints and Contact information**

This is a brief overview of the study and additional questions are welcomed before you agree or decline to engage in the study. If you have any further questions do not hesitate to contact us at the University of Manchester.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk

**Researcher:** Katie Paddock School of Nursing, Midwifery & Social Work University of Manchester, 07790 251561

**Supervisor:** Prof. Chris Todd, School of Nursing, Midwifery & Social Work University of Manchester, 0161 306 7865

**Supervisor:** Dr Catherine Walshe, School of Nursing, Midwifery & Social Work University of Manchester, 0161 306 7649

Appendix 11: Inclusion and exclusion criteria for participants



# **Inclusion and Exclusion Criteria**

Study title: Transition to a care home: Identity and mental health in older people

Below are the inclusion and exclusion criteria for the study.

Please give an information sheet to those people who meet these criteria. If they express an interest in participating, either ask them to contact the researcher, Katie Paddock, or do so on their behalf. Contact details are on the information sheets.

### Resident inclusion criteria:

- Aged 65 years or older. No upper age limit.
- Resident in a care home.
- Have experience of a transition to long-term can and be able to recall their experiences.
- Must have the capacity to consent to participate.
- English speaking and have a sufficient level of literacy to read through and understand the information and consent forms.

### Significant other inclusion criteria:

- Relatives or long-term acquaintance of resident.
- Is able to answer questions about the residents' personality and features of his/her identity.
- English speaking and have a sufficient level of literacy to read through and understand the information and consent forms.

## Staff inclusion criteria:

- Managerial or care/nursing staff at a care home facility.
- Work with residents who are new to the care home, or adapting to life in a care home.
- English speaking and have a sufficient level of literacy to read through and understand the information and consent forms.

#### **Appendix 12: Consent form for residents**



### **Consent form – Residents**

Transition to a care home: Identity and mental health in older people

Name of participant: Participant code:

# Please initial each box to show you understand and agree with the statement

I confirm that I have read information sheet (Version 4: 28/05/2013) on the above project and have had the opportunity to consider the information and ask questions, and had these answered satisfactorily.

I understand that my participation in the study is voluntary and that I am free to refuse any questions and to withdraw at any time without giving a reason and without detriment to any treatment/service

I understand that no additional tests or medical procedures will be undertaken.

I understand that the focus groups and interviews will be audio-recorded.

I understand that anonymised direct quotes will be used in the write up of the study, with my consent.

I agree that any data collected may be passed to other researchers and that personal information may be scrutinised by an authorised person and information will be treated as strictly confidential.

I understand that the audio tapes will not be used or made available for any other purpose

than the research project and will be destroyed at the end of the study.	
I understand that the researcher will keep the discussions confidential and whilst participants will be advised and expected to maintain confidentiality, the researcher cannot personally guarantee confidentiality from focus group participants.	
I agree to take part in the study.	

Name of participant	Date	Signature
Witnessed	Date	Signature
I confirm that I have fully explaine	ed the purpose and nature of	f this study.
Signed	Date	
The research to be carried out ha	s been approved by the Unive	ersity of Manchester

The research to be carried out has been approved by the University of Manchester Research Ethics Committee.

The Northampton Research Ethics Committee has reviewed the study.

Data information collected in this study will be processed in accordance with the Data Protection Act (1998).

#### Appendix 13: Consent form for significant others



Transition to a care home: Identity and mental health in older people

Name of participant: Participant code:

# Please initial each box to show you understand and agree with the statement

 I confirm that I have read information sheet (Version 4: 28/05/2013) on the above project and have had the opportunity to consider the information and ask questions, and had these answered satisfactorily.

 I understand that my participation in the study is voluntary and that I am free to refuse any questions and to withdraw at any time without giving a reason and without detriment to any treatment/service

 I understand that no additional tests or medical procedures will be undertaken.

 I understand that the focus groups and interviews will be audio-recorded.

 I understand that anonymised direct quotes will be used in the write up of the study, with my consent.

 I agree that any data collected may be passed to other researchers and that personal information may be scrutinised by an authorised person and information will be treated as strictly confidential.

I understand that the audio tapes will not be used or made available for any other purpose than the research project and will be destroyed at the end of the study.

I understand that the researcher will keep the discussions confidential and whilst participants will be advised and expected to maintain confidentiality, the researcher cannot personally guarantee confidentiality from focus group participants.	
I agree to take part in the study.	

Name of participant	Date	Signature
Witnessed	Date	Signature
I confirm that I have fully explain	ed the purpose and nature of	this study.
Signed	Date	
The records to be carried out be	a been enpressed by the Unive	raity of Manahastar

The research to be carried out has been approved by the University of Manchester Research Ethics Committee.

The Northampton Research Ethics Committee has reviewed the study.

Data information collected in this study will be processed in accordance with the Data Protection Act (1998).

### Appendix 14: Consent form for staff



Transition to a care home: Identity and mental health in older people

Name of participant: Participant code:

# Please initial each box to show you understand and agree with the statement

I confirm that I have read information sheet (Version 4: 28/05/2013) on the above project and have had the opportunity to consider the information and ask questions, and had these answered satisfactorily.

I understand that my participation in the study is voluntary and that I am free to refuse any questions and to withdraw at any time without giving a reason and without detriment to any treatment/service

I understand that no additional tests or medical procedures will be undertaken.

I understand that the focus groups and interviews will be audio-recorded.

I understand that anonymised direct quotes will be used in the write up of the study, with my consent.

I agree that any data collected may be passed to other researchers and that personal information may be scrutinised by an authorised person and information will be treated as strictly confidential.

I understand that the audio tapes will not be used or made available for any other purpose

than the research project and will be destroyed at the end of the study.	
I understand that the researcher will keep the discussions confidential and whilst participants will be advised and expected to maintain confidentiality, the researcher cannot personally guarantee confidentiality from focus group participants.	
I agree to take part in the study.	

Name of participant	Date	Signature
Witnessed	Date	Signature
I confirm that I have fully explaine	ed the purpose and nature of	this study.
Signed	Date	
The research to be serviced out her	a been ennered by the Univer	aity of Manahaata

# The research to be carried out has been approved by the University of Manchester Research Ethics Committee.

The Northampton Research Ethics Committee has reviewed the study.

Data information collected in this study will be processed in accordance with the Data Protection Act (1998).

Appendix 15: Research poster



# Transition to a care home: Identity and mental health in older people

You have been invited to take part in a study run by the University of Manchester. The study aims to explore the experience of transitions to long-term care, and will include the points-of-view of residents, their friends/family and staff members of the care home.

If you and your friends/family agree to take part you will be asked to participate in individual interviews and focus groups. Questions will focus on the process of the transition, and how this has impacted on how you see yourself.

There will be observations occurring in the care home throughout the study period. The researcher will make notes on interactions in the care home. Those who do not wish to take part in observations should inform a member of staff, or speak to the researcher directly. The whole study, including analysis and write-up should last about two years.

If you think you might be interested in taking part, or wish to discuss the study further, please contact the main researcher:

Katie Paddock. Contact details are below, or you can speak to her when she is in the care home.

Katie Paddock	
PhD student	
Jniversity of Manchester,	
School of Nursing, Midwifery & Social Work,	
ean Mcfarlane Building,	



Observations are occurring in the care home as part of a study by the University of Manchester. The researcher will be in a communal area of the care home making field notes and audio recording events that arise. Please ask the researcher, Katie Paddock, or a member of staff if you require more information about this study.

We appreciate that some people may wish to withdraw their data from particular observations, i.e. not have what they have said included in the study.

# By completing this form you are choosing to opt out of one of these observations.

It is difficult to keep track of who enters and leaves a room during an observation, so in order to remove your data, we require some information about the specific observation.

Today's	date:

Date observation:	 	 	of
Which room?:	 	 	
Approximate room:		 in	the

Please hand this form to Katie Paddock, or to a member of staff at the care home, who will forward it to her.

Appendix 17: Initial topic guide for residents



## **Topic Guide – Residents**

### Moving to a care home

- Tell me about your move to the care home
  - How was the decision made for you to move here?
    How did this make you feel?
  - What were important things to consider?
  - Could anything have been done better?
- Tell me about how you felt after you moved here.
  - How did the staff/other residents approach you?
  - Was there anything they did that made you feel better/worse about moving here?
  - What would you have done differently?
- What would you consider to be a 'good' day for you?

### **Identity**

- How would you identify yourself?
  - What makes you 'you'?
  - What would you consider to be meaningful activities? E.g. Gardening, sport.
- Do you think you've changed since moving here? How?
- What were you like when you were younger? Is this different to how you see yourself now?
- How do you think other people see you now?
  - $\circ \quad \dots \text{your family} \quad$
  - $\circ \quad \dots \text{your friends}$

- o ...care home staff
- How much control do you have to engage in activities that are meaningful to you?
   o How does this make you feel?
- Do you think you have the chance to be the real you in the care home?
- How old do you feel? Is this different to how old you are?

Appendix 18: Initial topic guide for significant others



### **Topic Guide – Significant other**

### Moving to a care home

- Tell me about your friend/family members' move to the care home
  - How was the decision made for him/her to move here?
    - How did this make you feel?
    - How do you think they felt?
  - What were important things to consider?
  - What were your concerns?
  - What do you think their concerns were?
- Tell me about how you think s/he felt after they moved here.
  - How did the staff/other residents approach him/her?
  - What would you have done differently?
  - Could anything have been done better?
- What would be a 'good' day for them?

### Identity

- How would you define his/her identity?
  - What makes them 'them?
  - What would you consider to be meaningful activities for him/her? E.g. Gardening, sport.
- Do you think they've changed since moving here? How?
- What were they like when they were younger? Or before they moved to a care home?
- How do you think other people see them now?
   ... family

- $\circ$  ... friends
- ...care home staff
- How much control do you think s/he has to engage in meaningful activities?
- Do you think s/he has the chance to be their real selves in the care home?

#### Appendix 19: Initial topic guide for staff



### **Topic Guide – Staff**

### Moving to a care home

- Tell me about a time a resident moved here and how you were involved How was the decision made for him/her to move here? How do you think they felt?
- What were important things to consider before relocation?
   What were your concerns?

What do you think their concerns were?

- Tell me about how you think s/he felt after they moved here.
- How did you, other staff members and residents approach him/her?

What would you have done differently?

Could anything have been done better?

• What would be a 'good' day for them?

### Identity

• How would you define his/her identity?

What makes them 'them'?

What would you consider to be meaningful activities for him/her? E.g. Gardening, sport.

- Do you think they've changed since moving here? How?
- How do you think other people see them now they have moved to a care home?
- How much control do you think s/he has to engage in meaningful activities?
- Do you think s/he has the chance to be their real selves in the care home?

Appendix field notes

#### Appendix 20: Final topic guide for residents



The University of Manchester

## **Topic Guide (Residents)**

- Tell me about your move to the care home
- How was the decision made for you to move here? (How did this make you feel?)
- Good points/bad points about the move?
- What would you have done differently?
- How did you settle in? What helped you to settle in? How would you advise a new resident to settle in?
- Did you bring [m]any personal belongings with you? What did you bring and why?
- Was there anything they did that made you feel better/worse about moving here?
- What would you consider to be a 'good' day for you here?
- What makes you 'you'?
- What did you used to do before moving to the care home? (Hobbies? Work?)
- What activities do you do in the care home?
- Do you think you've changed since moving here? How? Why?
- What were you like when you were younger? Is this different to how you see yourself now?
- Do you feel like yourself/like you can be yourself in the care home?
- How do you think other people see you now?
- ...your family
- ...your friends

- ...care home staff
- Do you have many friends in the care home? Do you talk to any of the other residents? If not, why not?
- Do you get many visitors?

#### Appendix 21: Final guide for significant others



## **Topic Guide (Significant other)**

- Tell me about your friend/family members' move to the care home
- How was the decision made for him/her to move here?
- How did this make you feel?
- How do you think they felt?
- What were important things to consider?
- What were your concerns?
- What do you think their concerns were?
- How did they settle in?
- What helped them to settle in?/What would have helped them to settle in?
- Tell me about how you think s/he felt after they moved here.
- What would you have done differently?
- Could anything have been done better?
- Tell me about the staff in the care home. What are they like with the residents?
- What would be a 'good' day for them in the care home? What would you consider to be a good day here?
- What would you consider to be meaningful activities for him/her?
- Do they have friends in the care home?
- What makes them 'them? How would you describe them? Their personality?
- What were they like when they were younger/ Before they moved to the care home?
- Do you think they've changed since moving here? How?

• Are they able to be themselves in the care home? In what ways?

#### Appendix 22: Final topic guide for staff



### **Topic Guide (Staff)**

- Tell me about a time a resident moved here. How did they/their families feel about moving here? What helped them to settle in?
- What went well? Could anything have been done better?
- What are important things to consider before moving to a care home?
- Tell me about how you think s/he felt after they moved here.
- What would be a 'good' day for them? Either particular resident or in general.
- What makes them 'them'?
- How do you decide what activities to organize for residents?
- How do you incorporate individuality within the care home?
- Do you think they've changed since moving here? How? How have they adjusted, if at all?
- Do they get many visitors?
- Do you think s/he has the chance to be their real selves in the care home?

### Appendix 23: Coding framework

Theme	Code	Description	Examples		
Social co	ocial comparison				
	Not want to be like residents with dementia	Residents tended to compare themselves with other residents	"Wouldn't it be awful to have that – to be like that? To, you know, have dementia"		
	Compared cognitive impairments	Residents without dementia compared their cognitive abilities with the cognitive abilities of residents with dementia	"He said, 'it's a shame for 'em [residents with dementia]. It's not their fault. Now I might be getting forgetful in me old age, but I still have me marbles. Well, most of them anyway'. Louis laughed"		
	Compared independence	Residents compared their levels of physical independence against other residents' physical independence	"Some people in here, some of them, the ones who've lost their minds, choose not to do anything for themselves, you see. They couldI suppose some of them aren't able toBut I've never been one to do nothing"		
	Pity for care home residents for being in a care home	Residents, relatives and members of staff expressed sympathy towards residents	"Yeah it's not easy moving away from your home to a place like this. Leaving everything. I wouldn't like to do it."		
	Pity for residents without dementia to be surrounded by residents with dementia	Staff and relatives felt sorry for residents without dementia for living amongst amore impaired residents	" I feel sorry for her [Catherine] because she has to listen to these [residents with dementia] going on and on, doesn't she? I do feel sorry for her [inaudible] And Alwen never shuts up"		

Pity for residents with der		ing confusion and other here, yo	the poor souls [residents with dementia] that are in ou know, they're so nice. You know, I just feel sorry n"
Pity for residents with me health/learning disabilitie		ning disabilities for and lean they we resident nice guy	d said he felt sorry for the residents with dementia rning disabilities. He said it wasn't their fault that ere ill, and that it was a shame. He looked towards a t with a brain injury, and tutted. He said he was a y, and that it was a shame, and that living how he ust be terrible."
Acknowledgement of being resident		e not likely to ever leave other re more se suppose	n a care home. I'm not as bad as this lot [gestured to esidents in the communal area that appeared to have evere physical and cognitive impairments]. But I e that's who I am nowHe said 'places like this are beople like that'"
Independence and Autonomy			
They were more independ residents	<i>lent than other</i> Some residents consider more independent than	8	t be in here, but I can still look after myself. Not like t"
Other residents are depen	adent Some residents consider too dependent on staff		e of them in there, they won't even try and help f. Which you can understand at their ages, you

Independence important for identity	Residents considered independence and autonomy to be an important element of their identities	"being independent was very important to me. Very important."
Resident has been independent	The resident used to be independent in the past	"Oh me mum was always independent. She's always been independent."
Independence taken away	The resident's independence has diminished or been taken away	"Well – in some cases they have everything taken away from them. You know, whether that be finances, control of finances, control of their life, control of their social life, control of their – could be – drink habits, food habits. They have everything taken away and re-evaluated. And well, it's controlled isn't it in a way?"
Hired care made them feel independent	Residents who hired care staff felt independent and able to make autonomous decisions about their care	"April said she was fed up with having to wait for the staff all the timeShe said that she 'the girls' [hired care assistants] in her flat would get her up whenever she asked for itApril said she was fed up and wanted to go home 'You can't even get a cup of tea when you want one'"
Want to be more independent in the care home	Residents want to be more independent within the care home	"I mean I think it's very kind of them [the staff] and all that – but to me it's not helping me to get right. You see, because if they're going to do it for me, I'll never want to walk. That's why some of these people are old, you see. They can do better if they tried, but they don't try"
Doing tasks to stay independent/active/useful	Doing small tasks in the care home made residents feel more independent and useful	"Catherine re-entered the room and helped to place the cutlery on the tables. She told me it makes her feel "useful", even though she cannot walk about much", and added "I know I'm not completely independent anymore. But it's something"

	<i>Difficult to accept help but keep independence</i>	Residents found it difficult acknowledge their need for assistance from staff and their desire to remain independent	"It's difficult to keep some of them happy because obviously a lot of them need helpIt's all well and good saying they want to remain independent, but if you can't walk, you can't walkIt is our job at the end of the day – to keep them well"
	Confirm with staff to do tasks/Availability of staff	Residents had to confirm with members of staff before they could complete a task or engage in a particular activity	"Catherine told me that her son can pick her up and take her home for dinner or a family gathering whenever she wants, but it has to be 'okayed' by Tracey first."
	Care home made them more independent	Residents believed that living in the care home made them more independent	"This is the happiest time of me life. By being in the homeWell I've changed for the better because I'm more content. Since I've come in here I'm more content. I've got no worries, have I?"
Frustrati	on		
	Reminding residents of false memories	It was difficult to know whether to remind residents with dementia of reality or embellish their false memories	"Barbara told me that she once took Alwen outside for a walk and down the street to show her that they are not in Wales and that she cannot pop down the road to see her sister, like she thinks she can. Barbara had asked Alwen at the door of the care home which way they need to turn to get to her sister's house."
	Avoid other residents	Some residents would actively avoid other residents	"Catherine said that she did not know which room to sit in because she had Alwen in one room talking about Wales, and Marcus in the other talking about pool and music."

Symptomatic behaviour of resid	<i>dent</i> Behaviour that was symptomatic of dementia caused frustration	"Sometimes you put up with it. Sometimes you get fed upHaving to repeat yourself over and over again."
Funding	Care homes lacked funding and resources	" There can be conflictsAt the end of the day it is a company, and – – there is a hierarchy you know – it starts with the residents right here [indicates the bottom], and then it goes carers, and then it goes to the seniors, and then it goes to the managers, and then it can go to the a- but then it's not always the manager's fault, you know, you get area managers, um, who really hold the purse strings and things"
Compromise	Staff and residents had to compromise over elements of their care	"if there are twelve residents – 11 of them want to go to an art gallery, whereas 1 just wants to go to bingo, they'll probably go to the art galleryFrustrated. They get frustrated. But hopefully, you know, next time they'll do something that meets that person's social needs. And, so, then the other 11 are unhappy [laughs]."
Relatives do not think that care staff do enough	Relatives believed that care home staff could make more of an effort to support the residents or to create a more positive care environment	"Amanda [daughter of a resident], said that the DIY man still had not put the pictures up. Her friend also expressed dissatisfaction with the DIY man. He is apparently not very good, does not get much done, and can be rudeThe staff have not done anything about it."

Relatives argue with staff	Relatives have argued with staff about aspects of care	"Odette told me that Richard's son and her had an argument a little while ago. She laughed as she said he had called her a fat bitchShe said they're ok nowBut the son was apparently upset with his dad's care and lashed out. It was apparently a misunderstanding and there wasn't an actual issue with care"
Relatives felt that care home staff did a good job	Relatives were positive about staff performance, whilst acknowledging that they were often understaffed	"They're very good here. Very good."
Infantilising residents	Staff treated care home residents like children	"Sometimes it sounds like the staff are talking to residents [with dementia] as though they are stupid. It feels awkward. Like they're talking to a child." Quote from reflective diary in field notes "They talk to me like I'm stupid in here. But I'm not."
Not want to be in the care home	Residents did not want to live in the care home	"Julia just said that 'I don't want to be here' and lifted her arms to show the room and added 'look at them. Look at this lot. Bloody mad the lot of them'Julia seemed to be getting angry, so I didn't question her further" "I don't want to fucking be here"

	Asking	Residents disliked having to ask staff for help with most tasks	"Asking. You have to ask for everything here. They decide whether you get it. Doesn't matter what you want."
	Staff frustrated with residents	Staff became frustrated with residents	"Holly was calling out "Please Mrs" to everyone who walked passed her. The staff were rushing around trying to sort out lunch and were bringing in all the residents with mobility issues. Holly reached out and continued to call "please Mrs". Nancy walked passed her as Holly called out again, and Nancy looked at me and said, somewhat annoyed 'oooh, what's the matter now, [Holly]?". She walked away and rolled her eyes, sighing heavily. She looked annoyed"
Ageing a	and changing		
	Impact of physical infirmity	Residents' physical impairments and advancing age impacted how residents considered themselves	"But me arthritis got me worse - me back got worse. After that I couldn't get out. And there was a nurse that used to be here, and she'd say 'you get out as much as you can [Sandra]. One day you might not be able to get out". And them words have come true. But we go on days - the manager takes us on days out. She gets a minibus and takes us to the markets."
	Residents became more physically impaired	Residents became more physically impaired as they got older	"Ageing Is a terrible thingYou can't do what you used to do"
	Change environment to accommodate infirmity	Residents changed their physical environment or habits to accommodate their impairments	"She [Meredith] said she had to move the coffee table out of her living room because she was worried about falling again. She had to move a lot of the smaller pieces of furniture out of the way to she felt safer moving around her home"
	Personhood and dementia	Others did not consider a person with dementia to be the same person they used to be	"that lady disappeared – the lady in there is not really me mum. There's not much of her that I recognise about her now."

onality vs. care home		
The care home is not a home	They care home was not considered to be the same as, or as good as, one's own home	"So - I mean - as much as - any home's a home, it's technically not - because it's not their home anyway. It's kind of like a test tube baby"
Miss own home	Residents missed their own homes	"This is my home. Now. I suppose. Well, I live here anywayI miss me flat. It's not quite the same here"
Food and drink	The care homes had routines around food and drink	And she still loves her bread and jam now, yeah [laughs]. Well this is it you see, isn't it? It's something Which i nice, that they do it for her"
Staff know resident personality	Staff knew elements of residents' personalities and tried to incorporate this knowledge in their daily care	"Barbara knew a lot about what man of the residents were like before they came to the care home."
Preferred names	Residents had preferences for how they were addressed by others in the care home	"Edna said the resident prefers being called Mrs B, becaus he doesn't like people using her first name"

Residents told to adhere to routines	Staff believed that residents should adhere to the daily routines of the care home	"She said 'I don't like it here'. I asked why. She said she had been at the care home for about three years and dislikes it because they are very strictShe wants to go to the park, but the staff won't let her."
Compromise	Residents and staff had to compromise between residents' desires and the structure of the care home	"Meredith told me there was a bit of compromise with the staff. 'Mostly with the little things, like a cup of tea, you know.' 'It's a different routine from home'She said she understood that they were understaffed and couldn't accommodate everyoneMeredith said that they sometimes make you a sandwich 'if you're peckish and they're not too busy', otherwise you have to wait"
Staff adjust routines for individual residents	Staff amended daily routines to accommodate residents' individuality and preferences	e.g. duvet day
Clothing and identity	Clothing was important for a resident to express their personality and identity	"She said she did not like it because it was too big. I mentioned that she was all matching, as she was wearing a pink jacket, red leggings, and a pink jumper. She said that she likes to match"

Staff put resid not usually we	ents in clothes they would ear	Care home staff dressed more impaired residents in clothing that made the caring role easier,	"Alwen had soiled herselfBarbara sighed and told me she'd only just changed her about an hour ago, and put clean trousers on herBarbara joked that getting the trousers off Alwen was a difficult task, but then added 'but she likes wearing them. She doesn't like those jogging bottoms or anything, so I like to put her in her trousers. It's how she's comfy'"
Residents had	no belongings	Residents did not bring any belongings to the care home	"I didn't have anything. Well I did and I didn't. I flogged it and got the money for it. To pay here"
Residents can	bring personal possessions	Care home staff allowed residents to bring personal items to the care home	"It's something we really try and promote here. I say to the families, 'don't look at a room as if it's for you to sleep in. You've got to look at it as if it's for your parent to stay in, so please do bring in their own bedside table, their own lamp – cos they put that lamp on for the last 12 months. They're used to that lamp. Bring in all the little knick-knacks. All the cherished little ornaments and bits and pieces"
Possessions li	nked to memories	Personal possessions were anchors to residents' memories, particularly identity-relevant identities	"Richard told me about how he used to be a photographerRichard said that he wished he had kept his old camerasthey reminded him of some interesting times in his life. But he cannot use them anymore, especially not in the care home. 'What would I take pictures of?'."
Photographs a	und memories	Photographs were important anchors to memories, particularly for residents with dementia. Relatives wanted residents with dementia to keep photographs to keep memories alive	"Amanda said that it was important for her mother to have photographs of her family up on the walls in her room so that she can remember who everyone is. As she does not see her grandchildren very often, Amanda was worried that Carrie would forget what they looked like or forget their names"

Not appreciate possessions due to cognitive impairment	Residents with cognitive impairments were not able to appreciate their personal possessions or make connections with relevant memories	"They don't – it's not as if they need possessions round them, it's just like, even if there was stuff there they wouldn't notice itThey [residents without dementia] like to have these familiar things around them, and it's like made their home here now. Other people it's like their minds have gone that far that whatever you put in their rooms, it wouldn't register that that's from their life before they came in [Care Home 02]. They don't miss it. They never say 'oh I wish I had a few more photographs of my family here. You know what I mean? They never ask for things like that to be honest."
New possessions in the care home	Residents acquired new possessions whilst in the care home	"Marcus told me that he was "so happy" and I asked why. Tracey had bought him a radio for his room so he can listen to his music. He then listed a few genres and artists who he liked to listen toHe repeated that he was "so happy". He told me that he tries to catch Tracey out by naming obscure jazz players, but she knows most of them – and laughed."
Care home not personalise rooms	Care home staff did not help to personalise residents' rooms	"We were promised when we got here that this carpet would be refitted, cos it looks a mess Never has been. Little things about the room – I think this room needs redecorating"

Can't converse with other residents	Residents without dementia were unable to converse or establish relationships with residents with dementia	"Wellyou couldn't make a conversation with none of them"			
Residents made friends with other residents	Residents felt they had formed friendships within the care home, which they valued	"Oh aye, I got a good friend here. He's a good friend, a good mate. We get on well together"			
Few visitors	Residents did not receive many visitors	"I asked a member of staff about how many visitors the residents getShe said most don't get anyI asked whether she knew much about the residentsShe said 'not really', other than what is on the care plan, or similar paperworkShe added that the residents [with dementia] sometimes tell her little stories about when they were younger while she is doing care 'The families usually tell you bits about them, and they do when they come in, but if they don't come in for ages you don't learn anything about them as people'"			
Regular visitors	Residents had regular visitors	"Me sons come everyday – Yeah, and they never miss."			
Compromise	Residents had to compromise with activities, as many had different interests, and the care home could not accommodate a variety of activities	"People don't like the same things as I do, or I don't like the same things as they do."			
Watching television	Residents watched a lot of television in the care homes	Multiple field notes of residents sat in front of a TV			
Staff organise activities in the care home	Staff organised activities for residents within the home	"There were leaflets on the wall about a barge tripA member of staff said she was trying to organise taking the residents out on a barge for the day"			
Staff do not organise activities	Staff did not organise for care home residents	"Well they don't do very much. When I first come up here they used to have bingo, once a week. But since she's been here (Tracey), she doesn't do it now, but we used to do. Have bingo, and erm, play bingo for prizes. And I was always winning [laughs]."			
<i>Residents cannot be bothered with activities</i>	Residents did not feel motivated to engage in activities or request that staff organise activities	"I asked Louis whether there were any activities he wanted to do in the care homeHe said he couldn't be bothered and that there was nothing to do"			

Missed engaging in previous activities	Residents missed engaging in activities that they had enjoyed prior to the transition to a care home	"Take him to the pub for a few beers. Which, that's what he misses the most we take him to the pub down the road – for his tea and a couple of beers, which he loves, but it's hard working getting him – or taking him in the car, getting him in and out of the car. Nothing's as easy as what it seemsHe used to like going to the local pub with hi friends. Just sat there having a natter and"
<i>Difficult to organise activities in light of residents' care needs</i>	Residents' physical or cognitive impairments influenced the types of activities that staff were able to organise	" It's hard to think of where they can go really. You got to think about where they're going to go to the toilet and everything – so there's loads to think about before you even take them out."
Start new hobbies	Residents started new hobbies within the care home	"I never crocheted til I came here. I really enjoy it."

	Mar-13	Apr-13	May-13	Jun-13	Jul-13	Aug-13	Sep-13	Oct-13	Nov-13	Dec-13	Jan-14	Feb-14	Mar-14
Care													
Home 01													
Care													
Home 02													
Care													
Home 03													

### Appendix 24: Gantt chart of data collection period

Day	Time of shift	Care home	Care home	Care home
-		01	02	03
Monday	Early (8am-	10.5	10	3
· ·	2pm)			
	Mid (2pm-8pm)	12	7	2
	Late (8pm-8am)	1	2	1
Tuesday	Early (8am-	12.5	9	4
	2pm)			
	Mid (2pm-8pm)	9.5	10	3
	Late (8pm-8am)	2		
Wednesday	Early (8am-	12.5	8	3
	2pm)			
	Mid (2pm-8pm)	13.5	6.5	2
	Late (8pm-8am)	1.5		1
Thursday	Early (8am-	10	12.5	3
	2pm)			
	Mid (2pm-8pm)	13	12.5	3
	Late (8pm-8am)	1.5	1.5	
Friday	Early (8am-	8	11.5	4
	2pm)			
	Mid (2pm-8pm)	5.5	7	3
	Late (8pm-8am)	1	1	1
Saturday	Early (8am-	6	3	3
	2pm)			
	Mid (2pm-8pm)	7.5	4.5	2
	Late (8pm-8am)	1	2	
Sunday	Early (8am-	4.5	5	
	2pm)			
	Mid (2pm-8pm)	4	7.5	
	Late (8pm-8am)		1	

Appendix 25: Overview of days and shifts that observations were conducted

**Appendix 26: Findings report for care homes** 



# The impact of the transition to a care home on residents' sense of identity

## **Findings Report**

## Katie Paddock, University of Manchester

Supervisors: Prof. Chris Todd, Dr Christine Brown Wilson, Dr Catherine Walshe

#### **Executive summary**

#### Background

The transition to a care home is often a difficult period for older people and their families. The move entails multiple changes, and can have a negative physical/emotional impact on the individual. Such changes threaten an individual's identity, which can lead to poor well-being. But there is limited information on how these issues influence a residents' identity, and how they engage in identity-management in long-term care.

#### **Objectives**

To explore how the transition to a care home impacts residents' sense of identity over time.

#### Method

Three care homes of varying sizes and in different areas of the North West of England were investigated using a qualitative case study approach. Semistructured interviews were conducted with care home residents, relatives, and members of staff, with observations (approximately 300 hours) over twelve months. Framework analysis identified themes within and across cases.

#### Findings

- Moving to long-term care had a negative impact on residents' sense of identity.
- Independence was a significant part of residents' identities, but moving to a care home made them feel dependent and childlike.
- Small tasks, such as answering the door to visitors or setting the table for meals, promoted a sense of independence within the care home. This made the residents feel happier and more 'at home'. Nonetheless, there were particular tasks that always required staff involvement (e.g. medications).
- Some members of staff were adept at promoting residents' sense of self within the care home by occasionally altering the daily routine of the care home for particular individuals, e.g. allowing duvet days or alternative meals.
- In order to promote a positive identity, residents without symptoms of dementia compared themselves to residents with symptoms of dementia.

• Staff sometimes became frustrated with residents, and vice versa, often due to a sometimes over-tasked/under-staffed workforce.

#### Introduction

In 2013, you participated in a study as part of my PhD at the University of Manchester. The study explored the impact of the transition to a care home on residents' sense of identity over time. I really appreciate your cooperation and input throughout the study. I conducted over 300 hours of observations across three care homes over the course of the year. Below is a brief summary of the findings. Some of these findings might be familiar to you or describe themes that you were already aware of, but I hope they shed light on different perspectives. Though I have used small quotes, to maintain the confidentiality of participants, I have not included detailed quotes or descriptions.

#### Aims & objectives of the study

- Explore how the transition to a care home impacts residents' sense of identity.
- Understand the factors that influence any changes in perceived identity, from the perspective of the resident, their significant others, and care home staff.
- Explore the maintenance of identity within the care home setting.

#### Findings

Though the transition to a care home had an impact on residents' sense of identity care home staff made efforts to promote their sense of self in the home. Four major themes that describe how the transition to a care home influenced their sense of identity emerged out of my analysis:

#### Independence

Residents felt that independence was an important element of their identity throughout their life. Most relatives also stated that their family member had "always been" independent, and seeing them in a care home and/or in a more dependent state was a shock. The move to a care home meant that residents were no longer in charge of daily and meaningful activities, such as making a drink/meal, housekeeping and engaging in hobbies. It was often difficult to strike a balance between the physical needs of the residents or policies/routines of the care homes, and residents' wishes. Many residents lamented that they were not able to complete tasks themselves, some because of their cognitive/physical impairments, and others because the rules of the care homes prohibited it, even if they felt they could manage. This made them feel childlike and dependent, though they appreciated that the staff were helping. Certain tasks unavoidably needed staff involvement (e.g. medications or making phone calls), or residents' impairments meant they regularly needed help, but residents told me that they often felt that they could not or should not ask for assistance from staff when they were particularly busy, because they did not want to "rush" the staff or make them angry. The residents appreciated how busy staff were and often did not want to trouble them.

Nonetheless, most residents valued the opportunity to maintain their independence within the care home, e.g. putting out the cutlery for mealtimes, helping with teas during breaks or answering the door to visitors. Small tasks such as these made them feel "useful" and "[broke] up the day", otherwise they felt like they were not "doing anything" every day. Other things that made some residents feel more independent within the care home were: having their own

key to their room, being able to make themselves a [hot] drink, being in charge of ordering their own medications and/or booking doctors appointments, taking themselves to the toilet, being allowed to go to local shops with/without supervision, and helping with other small tasks in the care home. Particular members of staff were adept at incorporating their knowledge of individual residents' abilities and preferences in to their daily care. One resident even stated that certain members of staff made an effort to keep particular tasks 'free' for him/her to complete, because they knew it meant a lot.

#### Ageing

Residents stated that the ageing process made them acknowledge that they could no longer complete certain daily tasks or engage in particular activities. Whilst still living in their own homes, some residents admitted to moving furniture from a room or they did not go in to certain rooms in their homes out of fear of falling or because climbing the stairs became too difficult. The need for these changes highlighted that they were getting older and more frail, but they were still in control. The move to long-term care had a comparatively larger impact on their sense of self, according to participants. Residents believed that moving to a residential or nursing home emphasised their frailty because it involved other people (relatives, healthcare care workers etc.) telling them that they could no longer cope alone.

The ageing process also impacted their daily lives in other ways. Those who previously enjoyed social activities were left feeling alone after the death of their friends, or if they moved to long-term care. It was even more difficult to maintain these social ties within long-term care and most residents did not feel they had any friends within the care home. Deteriorating health also meant that residents did not feel that they could engage in the same activities anymore and they likened the care home to a waiting room where older people were "stuffed" prior to death. They highlighted that they 'couldn't' do anything and also weren't allowed to do anything because of the restrictions within the care homes.

#### Making comparisons

Some residents were able to develop a positive sense of self in the care home. Most residents were initially unhappy about the idea of moving to long-term care; first because of the negativity around care homes in the media, and because it reminded them that they could no longer do things as they once could. Some described themselves as feeling "useless" and "decrepit". Therefore, moving to a care home initially had a negative impact on how they viewed themselves and thought others' viewed them.

However, they were able to promote a more positive identity for themselves by comparing themselves with other residents in the home. Those without a serious cognitive impairment, such as dementia, would compare themselves (specifically comparing their cognitive status) with residents *with* a form of cognitive impairment. According to all participants, older people with a form of dementia represented the worst part of ageing. Residents did not want to be associated with people with dementia, as they felt that other people (such as staff) would think that they were "as bas as them". By dissociating themselves from residents with dementia, residents were able to promote a comparatively positive view of themselves; saying things along the lines of "I might be in a care home, but at least I still have my marbles", or "I'd hate to be like them [resident with dementia]".

Residents with cognitive impairment were not aware that these comparisons were taking place. Anyone who made these comparisons were mostly vocal about it when the others were out of earshot, in order to avoid hurting other people's feelings.

#### Frustration

Residents without a cognitive impairment would sometimes become frustrated with those residents with a cognitive impairment, largely because of the repetitive or destructive behaviours of the latter. Even though residents were aware that those with dementia were not behaving in a particular way 'on purpose', such behaviours became wearing over time. Members of staff also became frustrated with residents, particularly residents with cognitive impairments, again because of their often repetitive or difficult behaviours. Residents with more advanced physical and cognitive impairments naturally require more attention from staff. However, staff were often very busy with multiple tasks, and it was difficult for them to provide sufficient attention to everyone. For example, in one care home, a resident repeatedly and loudly called out for assistance. Care staff were busy with other residents and tasks at the time and had acknowledged that they would see to him/her shortly. The resident continued to shout for attention very loudly, which caused some members of staff to become stressed and 'snap' at them. This frustration was due to a combination of the loud, repetitive behaviour of the resident, and an over-tasked and under-staffed workforce at that time.

Residents would become frustrated with members of staff because they felt that they were not receiving sufficient attention. There were regular disagreements between staff and residents over this issue, which sometimes caused tension within the home. For instance, one resident needed some help with their medication, but felt that they could not call for a member of staff because they were busy doing other tasks. The resident said it was annoying that s/he had to wait for assistance so often. Most residents felt that more could be done to meet everyone's needs, but appreciated that staff were busy with limited resources.

Frustrations were largely due to either an annoyance with the behaviour of residents with cognitive impairments, or differing expectations of care: first, residents feeling they were not receiving sufficient attention or care; second, staff feeling over-tasked and that some residents were too demanding.

#### Personhood

This theme arose in interviews and observations with all participants. Relatives in particular would state that their parent with dementia was "not the same person" they once were prior to being symptomatic. Due to behavioural changes and a deteriorating memory, residents with dementia acted differently to how they once did. Care home staff even noticed a difference in behaviours etc. in residents who developed dementia over the course of their stay at the home. Knowing the resident with dementia prior to their diagnosis highlighted the changes in their behaviours and their cognitive decline. Losing their memories impacted social ties, even to close family members, which greatly upset those relatives.

Relatives and members of staff agreed that it was sometimes difficult to see the person a resident "once was" in light of their changing and sometimes problematic behaviours. This was particularly difficult with residents who did not receive many visitors, who would retell stories and highlight elements of the residents' lives pre-diagnosis. During interviews, staff members stated that once they learned more about a resident with dementia, and were not too 'stressed' with multiple tasks, they appreciated the person behind the symptoms. Many staff made similar statements regarding residents without dementia. This enabled them to engage in more person-centred care, which ultimately benefits the residents, but also made staff feel like they were doing a better job at caring for each resident.

#### Home vs. care home

There were some comparisons between the care home and residents' own homes, and the routines associated with each. Staff and relatives often stated that they thought a care home should feel like the residents' own home. Residents echoed this sentiment, but added that though they knew the care home was their 'home' (as in the place they now lived), it did not always feel like *their* home. In reference to this, many residents pointed out the size of their rooms, where the majority of their belongings are kept, in comparison to the houses or flats they owned before. Residents often said "it'll do" in reference to their rooms and acknowledged that their rooms will never feel like "home". Where possible, the care homes allowed residents to bring their own furniture, which most residents appreciated. Some care homes decorated communal areas with current and past residents' items. Most believed this to be a "nice touch". Some members of staff were adept at incorporating individual routines to the daily care, where possible. For instance, one resident had allegedly had jam sandwiches for dinner everyday since they were a child, and the care home made an effort to do this as much as possible. Another care home acknowledged that some residents wanted a "duvet day", "like we all do sometimes", and did not get them out of bed at the usual time. If a resident did not want a meal that was offered that day, some staff made an effort to make them a meal they wanted. Small touches like these meant a lot to residents and their relatives, as it showed that the care home really cared about the individual residents and learned about them. However, it was often the case that the routine of the care home or available resources meant that this was not always possible for everyone, and some members of staff made more of a conscious effort to accommodate individuality than others. Nonetheless, small changes such as these helped to reflect the multitude of identities within the care home.

#### Conclusions

Though moving to a care home appears to have a negative impact on residents' sense of identity overall, staff can help residents to feel more "themselves". This can include incorporating small changes to the daily routine of the care home, learning about each resident as an individual, and promoting independence and individuality. Seemingly minor changes, like being allowed a cup of tea when they want one, rather than waiting for an allotted 'tea time' made residents feel more in control of their surroundings. Though it often might be "guicker and easier" for staff to complete a task themselves, such as answering the door or setting the table for mealtimes, some residents valued the feeling of being "useful" felt more able and less "decrepit". Nonetheless, there were particular tasks that always required staff input, or residents who needed more attention. Many staff members felt too over-tasked to provide sufficient attention to each resident, and the latter echoed this by occasionally feeling like they could not ask for assistance. Overall, particular members of staff were excellent at communicating with residents and their relatives in organising daily care to meet their expectations, including their physical and emotional needs.

Thank you again for participating in this study. I hope the findings were interesting and useful. I am currently writing up my thesis, but once it is submitted, I would be happy to send you a copy, which contains a much more detailed analysis.

#### **Contact information**

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