



*Exploring the meaning of care in nursing care homes for older people*

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# **Exploring the Meaning of Care in Nursing Care Homes for Older People**

Heather Dorothy Dunn

A thesis submitted in partial fulfilment of the requirements of  
Sheffield Hallam University  
for the degree of Doctor of Philosophy

June, 2021

## Candidate Declaration

I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.
2. None of the material contained in the thesis has been used in any other submission for an academic award.
3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.
4. The work undertaken towards the thesis has been conducted in accordance with the Sheffield Hallam University Principles of Integrity in Research and the Sheffield Hallam University Research Ethics Policy.
5. The word count of the thesis is (78,749).

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## Abstract

**Background:** A burgeoning ageing population (age 65+) and concerns over malpractice and abuse of older residents living in nursing homes pose unique challenges for health and social care service commissioners and providers. Yet little is known about this context or staffs' and older residents' views of nursing home care in the United Kingdom (UK). The aim of the present Health Psychology doctoral research was to explore wider contextual influences on care delivery at organisation level; explore staffs' and residents' perspectives of the meaning of 'care'; and identify barriers and facilitators to the delivery of this 'care' ideal.

**Methods:** A Critical Realist and qualitative approach examined contextual and embodied influences on UK nursing home provision at national, organisational and individual levels. **Participants** were three nursing homes for older people in North England, four care staff, and fourteen residents. **Data:** Ethnographic observations, visual methods (photo-elicitation), and object-elicitation were adopted during data collection. The data corpus included a literature review; photographs and researcher observation field notes; and orthographic transcriptions from a focus group with nursing home care staff and interviews with residents. **Analysis:** The data corpus was analysed using Thematic Analysis (informed by Braun & Clarke, 2006) from a critical stance. **Findings:** At national and nursing home organisational level care was structured around risk-averse and rationalised ('for profit') discourses, and represented a medical model of care. Rationalised, prohibitive, medically-driven care provision was found to conflict with nursing home staffs' and residents' positioning of appropriate 'care', which was more aligned with relationship-centred models of care. Recommendations for future research and practice are made in light of present findings.

## **Acknowledgements**

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## Introduction

I begin the thesis by outlining the focus of the research and providing a reflexive account of the origins of the work as it relates to my own personal experience as a nurse. A brief consideration of the broader context in which the thesis is positioned is then offered. Finally, this introductory chapter ends with an overview of the chapters that follow, and a summary of the research aims and questions.

### Background:

During the last twenty years the United Kingdom (UK) has witnessed significant demographic change. Improvements in healthcare have resulted in an increasingly older population, and the number of individuals aged 85 and over is projected to double from 1.6 million in 2016, to 3.2 million (4%) by 2041 (Office for National Statistics, 2017;2018). This population, defined as the 'older old' (Cohen-Mansfield, 2013) are the highest recipients of long-term nursing care.

This increase in the older population combined with a reduction in National Health Service (NHS) long term care beds for older people (Kerrison & Pollok, 2001), increased demand for private sector nursing home care in the UK during the 1990's (Wood & Baine, 2001). Subsequently the number of social care home beds increased from 363,000 in 1988 to 458,000 beds in 2016: a total increase of 26% (Ewbank, Thompson & McKenna, 2017). By 2011, there were 4, 608 general nursing homes in the UK (Care Quality Commission, 2011(a)) with 291,000 older residents (Office for National Statistics [ONS], 2014): increasing to 458,000 residents by 2016 (Ewbank et al., 2017). Although the number of male residents rose by 15.2% and fell by 4.2% for women, the average ratio of male to



female residents remained at 1:3 (Office for National Statistics [ONS], 2014). Financially, care home staff costs account for 45-60% of care home fees charged (Laing, 2002), and by 2017 was equivalent to approximately £12.04 billion in pay per annum (National Audit Office, 2018). This is greater than the NHS elderly and general nursing services £11.2 billion annual pay bill for nurses and care assistants (NHS Digital, 2018).

### Concerns about the delivery and regulation of nursing home care in the UK.

Although statistics demonstrate the huge scale and cost of nursing home care provision in the UK, it is generally acknowledged and research supports that older people dread losing their independence and having to live in a care home (e.g., Care Services Efficiency Delivery [CSED], 2007; and Clouston et al, 2013). Reduced independence commonly occurs with longevity due to physical and cognitive impairments associated with ageing that leave individuals increasingly dependent on others, and thus more vulnerable (e.g., Clouston, 2013). This problem is exacerbated by concerns about age discrimination in the provision/delivery of care at home (homecare) resulting in older people receiving less support to live independently at home, which means individuals require nursing home care sooner (Equality and Equal Rights Commission, 2011). Dread of institutional-based care is supported by reports of the poor care standards and even abuse in care provision for older people in both the NHS, and private sector residential care services in the UK (e.g., Care Quality Commission, 2015, 2017(a)(b), 2018(a)(b); 2019; National Audit of Dementia, 2011; Kenyon & Chapman, 2011; and Quigley, Jupp & Plomin, 2019): such issues are outlined in more detail below.

Although the primary focus of this thesis is private sector nursing home care provision in the UK, it is also important to note concerns about NHS care services for older people as Health and Social Care services became inextricably linked under the Health and Social Care Act (2012). The act requires the Department of Health (DOH), NHS England, Public Health England, and Clinical Commissioning Groups (CCG's) to collaborate in order to minimise health inequalities in services between people in England. The need to integrate care services for older people living in nursing homes is especially important as they were found to have 40-50% more emergency admissions and Accident and Emergency attendances than the general population of the same age (Sherlaw-Johnson, Smith & Bardsley, 2015).

Below are some examples of concerns and instances of prejudice, poor care delivery, and actual abuse towards vulnerable and older people within Health and Social Care services that have been raised since the commencement of this doctoral research in 2010:

**First**, the National Audit of Dementia (2011) conducted across hospitals in the UK found multiple aspects of the care of patients with dementia was inconsistent and inadequate including: staff to client ratios; person centred care; application of admission and discharge policies; prescribing of anti-psychotic drugs; risk assessment; staff training on care of those with dementia; nutritional management; environment; involvement of relatives in care planning; staff communication and discharge support; and poor overall dementia care management and co-ordination of good practice both within and between hospitals.

**Second**, the latest report by the Care Quality Commission (the regulatory body for adult Health and Social Care services) on the state of care services for 2017/18 (CQC, 2018b), found that: 1.4 million older people are unable to get the care and support they need; 1 in 6 adult social care services required improvement; and 1% were rated as inadequate. Also, services were impaired by 15% staff vacancy rates (110,000 vacancies) for nurses and social care workers leading to poor staffing and the use of often untrained agency staff that are unfamiliar with patient's resident's individual care needs.

**Third**, the Care Quality Commission reported government cuts in social care funding and high rates of older people requiring social care funding (77% in the North East, and 54% in the South West) had contributed to a 1.4% decrease in nursing homes since 2016/17. However, following investigations by The Guardian (Murphy, 2018), at least 44 out of 220 care homes in England that the Care Quality Commission had given the lowest rating (i.e., 'inadequate'), were found to be owned by companies with a combined profit of £113 million, many of which were in receipt of government (social care) funding for residents. This may suggest that 'for-profit' providers themselves are in a position to invest more in subsidising care beds for older people in order to offset the shortfall in Local Authority budgets. The tendency of private sector nursing home providers to prioritise profits over service quality confirms concerns voiced thirty years ago (e.g., Shadish, 1989). Indeed, concerns were realised when one of the UK's largest private sector care home providers Southern Cross, became insolvent in May, 2011, with the failed business plan potentially making 31,000 older residents homeless and without care, and hundreds of care staff unemployed. Fortunately, 600 of the 752 Southern Cross residential homes and nursing homes were taken over by existing UK care home providers with the remainder staying under the

management of Southern Cross. MPs on the Public Health Committee shared fears that this could happen again (Beckford, 2011), especially as a survey of UK nursing homes found over 28% of nursing staff surveyed reported their care home had changed hands in the last five years due to financial difficulties (Royal College of Nursing [RCN], 2010).

**Fourth**, people living in residential (rather than nursing) care homes in England are not eligible for NHS funding (i.e., Funded Nursing Continuing Care - FNCC) to pay for nursing care if their condition deteriorates: instead, they must move into a nursing home to receive contributions. This is a concern as evidence suggests that moving care home residents to alternative accommodation increases their stress levels (Shultz & Brenner, 1977), especially for residents with a behavioural problem (Grant, 1985). Inflicting such stress may be considered a breach of consumer rights for NHS patients (Wild, Szczepura & Nelson, 2010), and could increase negative physical and psychological outcomes (Lieberman & Tobin, 1983), and mortality rates of residents (Forder & Fernandez, 2011; Rothera, Jones, Harwood, Avery & Waite, 2002). Mortality rates have been shown to be highest in the first few months following admission to a care home: particularly for men, those with greater cognitive and physical impairments, and also for nursing home residents compared to those in residential or mixed care settings (Forder et al., 2011).

**Fifth**, in response to previous concerns over inappropriate nursing home service delivery and poor care practice, the service user advocacy organisation Healthwatch (formerly known as Local Involvement Networks [LINKs]), was established as a statutory service commissioned by local councils under the Health and Social Care Act (2012). Healthwatch representatives were

empowered to enter and view adult health and social care service providers, report on their findings, and providers are legally obliged to respond to and act upon such communications within 28 days. In one city-wide examination of residential and nursing homes for older people findings suggested shortfalls in care services including: mobility equipment provision; foot care; dentistry; and eye checks for residents (Sheffield Local Involvement Network, 2011 p23). Findings were partly due to under-resourcing and insufficient health professionals within these services to meet demand. Further areas for improvement identified were a lack of staff training in areas such as age awareness. Thus, improved communication between commissioners and Health and Social Care service providers is recommended to ensure sufficient and appropriately resourced services are available to meet service user demands (CQC, 2018b).

**Sixth**, in October 2010, due to inadequate care service and care delivery, there was a re-structuring of the assessment processes of the Care Quality Commission, which is the regulatory body in England that monitors and enforces National Minimum Standards [NMS, 2002] of care in nursing homes for older people. The re-structuring changed the way nursing homes were inspected and assessed and included the transfer of much of the responsibility for 'on site' care home inspections to Local Authorities and local NHS Trusts, who in turn disseminated information to the Care Quality Commission. This aimed to reduce duplication of site inspections and paper work, but was generally perceived as a streamlining and cost-savings exercise that was ineffective and met with criticism from both consumer organisations and service commissioners themselves. In response to reports of poor care standards in long-term care institutions and a lack of response to complaints about these services, from April 2012 the Care Quality Commission's regulatory powers to intercept and instruct the rectification

of poor practice were strengthened. However, Care Quality Commission inspections rarely extend to routine inspections of long-term care homes at night unless in response to a specific complaint (Kerr, Wilkinson, & Cunningham, 2008).

**Seventh,** despite Care Quality Commission regulation of adult social care services, poor care standards including abuse and neglect of residents were found in care homes in England. For example, Care Quality Commission unannounced inspections of the Old Deanery care home (CQC, 2014(a); CQC [March] 2015) found a failure to meet eight out of nine key standards of care, and also reported improvements were required as it was not consistently safe, effective, caring, responsive, or well led. Shortly after the first Care Quality Commission inspection, British Broadcasting Company (BBC) undercover TV documentary 'Panorama' (BBC News, [April] 2014) revealed poor care, neglect and abuse (assault) of older residents leading to one staff member being sacked and seven suspended, and the ultimate imprisonment of three care workers for elderly abuse. Also, allegations of abuse of a male resident in Mulberry Court residential home and his subsequent death in 2018 were substantiated by Luton Borough Council. The Care Quality Commission placed Mulberry Court in special measures in May 2018 to improve services in relation to safety, effectiveness, caring, responsiveness and leadership: however, the latest inspection in January, 2019 (CQC, 2019) still rated the home as overall inadequate. BBC Panorama undercover investigators previously found similar abuse in long-term care of adults with learning disabilities, leading to arrest and later conviction of staff at Winterbourne View hospital (Kenyon et al., 2011), and again eight years later in Whorlton Hall care home (Quigley et al, 2019). Worryingly the Care Quality Commission rated Whorlton Hall as 'good' in its routine inspection in 2017 (CQC,

2017b) and again during a focused inspection in March, 2018 (Care Quality Commission, 2018a), which was conducted due to whistleblowing concerns about 'issues in staffing and patient safety, culture and incident monitoring' (CQC, 2018a: p5). Only 2 months before Panorama's findings that staff and managers had behaved abusively towards residents, and despite whistle-blower concerns, Care Quality Commission inspectors reported that Whorlton Hall staff 'were kind, caring and respectful towards the patients and knew the patients well' (CQC, 2018a, p7). Additionally, in the health care sector, issues of leadership and/or quality and safety issues were also found following a review of 14 NHS Trusts (Keogh, 2013), of which 11 were put into special measures. Again, the care provided by most of these NHS services was found by the Care Quality Commission to be 'good' (CQC, [August] 2014b). Considering that the Care Quality Commission routine and unannounced inspections have rated care services as 'good' that soon after revealed as abusive, suggests that the current regulatory system may not always accurately reflect day-to-day care provided, and also that abusive care exists primarily beyond the gaze of visitors or outsiders.

**Eighth,** Guidance for employers on whistleblowing procedures is provided by the Care Quality Commission (CQC November, 2013) and recommends that employee's respect employee's confidentiality by not revealing their identity to un-necessary parties. Where an individual employee has concerns about health or social care delivery in England the advice of the Care Quality Commission (CQC [December], 2011c) was to raise them initially with employers or representatives such as trade union or governing bodies (for example, the Nursing and Midwifery Council or Medical Council). Alternatively, concerns can be reported, either anonymously or not, to independent whistleblowing

organisations or the Care Quality Commission: although in cases of a criminal offence the whistle-blower's details are likely to be disclosed to other official bodies, such as the police. In April 2017, the 'Freedom to Speak Up' (FTSU) scheme was introduced encouraging NHS staff to report issues via Freedom to Speak Up guardians embedded in NHS Trusts in England. In the first year of the scheme (1 April 2017 to 31 March 2018) there were 7,087 cases raised in total averaging 43 cases per trust, and around 0.6% of the overall NHS workforce of 1,205,814 (National Guardian's Office [September], 2018). The National Guardian's Office (2018) reported that of all professional groups, most issues were raised by nurses (2,233 -31%) compared to groups with more authority such as doctors (459 – 6%) and those with less authority such as Healthcare Assistants (502 – 7%). The highest percentage of cases involved bullying/harassment (3,206 - 45%), second involved patient safety/quality (2,266 - 32%); third were cases raised anonymously (1,254 - 18%) and in the remaining cases (361 - 5%), speaking up was considered to have resulted in negative consequences. Despite the latter, 87% of the 2,407 respondents providing feedback, said that given their experience they would speak up again. This National Guardian's Office (2018) report provided the first figures of the scale of concerns about failings in the care system, but also cautioned that incidence alone does not reveal the seriousness of issues raised: for example, single doctors being responsible for hundreds of acutely unwell patients overnight.

Within social care, whistleblowing figures are more elusive, although a report obtained under a Freedom of Information request found that complaints from staff and relatives had increased from 22 per month in December 2010, to 556 in March 2012, and more than 4,300 complaints were made about the treatment of older people and disabled people in care between February 2011



and June 2012 (BBC News: 23 June, 2012). Complaints to the Care Quality Commission included levels of staffing, staff assaulting residents, refusing to take residents to the toilet, shouting at older and disabled patients, and ignoring call bells (BBC News, 2012). Although whistleblowing figures are of concern, they are also encouraging as they demonstrate staffs' and relatives' willingness to engage with the system. However, there remains an integral lack of confidence in the whistleblowing system due to historic failure to bring poor care practice to justice and/or improve services as a result.

Despite the aforementioned concerns about nursing home care in the UK, the experience of living in older peoples' nursing homes is under- researched. Negative psychological health outcomes for older residents (Flick, Garms-Homolová & Röhnsch, 2010; Pierson, 1999; Stewart, 1995) and poor care practice (as outlined in the aforementioned reports) demand critical exploration to inform understanding of what constitutes 'appropriate' institutional care. Building on author's previous qualitative research that suggests that care is aligned with a medical model that de-legitimises resident autonomy (Dunn & Moore, 2014) this doctoral research aims to inform understanding of how older people's nursing home care is constructed and the lived experience of residents and staff in this environment. It aims to develop recommendations that challenge dominant discourses about care delivery in older people's nursing homes, establish what, how and where power relations operate in their functioning, and the impact this has on both providers and recipients of care.

In this thesis a summary of existing literature (Chapter 1: contextual review) outlines: existing definitions, theories and models of 'care'; the current climate of nursing home care provision in the UK; concerns and reports of inadequate and inappropriate care Health and Social Care services; and the current system of

care services regulation. The ontological, epistemological and methodological approach the research is outlined in Chapter 2. The remainder of the thesis presents three studies carried out by the author in nursing homes for older people in England and triangulates findings with existing literature. The three qualitative studies include ethnographic observations (Chapter 3), a focus group with nursing home staff (chapter 4) and interviews with fourteen nursing home residents (Chapter 5). Findings of all three studies are discussed together (Chapter 6: 'Discussion of Findings') that concludes with final comments and recommendations. The aim of the thesis is three-fold: first, to determine what 'actual care' delivery looks like in context; second, to establish what 'ideal care' looks like from the perspective of nursing home staff and residents; and third, to determine whether there are any discrepancies between 'actual' and 'ideal' nursing home care, and offer suggestions on how (if such gaps in care delivery exist), they may be bridged.

#### Research Aims:

1. To explore within the framework of socioeconomic, political and cultural contexts the experience of residents and care staff in nursing homes for older people, and to explore the psychosocial dynamics of the carer-resident relationship.
2. To inform our understanding of resident's and staff's perception of the meaning of care, and critically examine the meaning of 'care' in the nursing home setting.
3. Critically examine the psychosocial dynamics between carers and residents taking into consideration wider socioeconomic, political and cultural contexts.
4. Determine what influences may impair or facilitate the delivery of care that is

aligned with the care ideology of residents living in nursing homes for older people.

5. Based on findings, potentially develop recommendations for future research and/or nursing home care service commissioners and providers that may enhance future care delivery.

#### Research Questions:

1. What discourses have influenced nursing home care provision, and what does this look like in practice?
2. What are nursing home residents' and staffs' perceptions of the meaning of care?
3. Are nursing home staffs' and older residents' perceptions of care aligned with existing definitions, theories, and models of care that are considered appropriate in the delivery of care for older people?
4. What influences bear on, or constrain the delivery of 'good' care in nursing homes for older people from the perspective of nursing home staff and residents?
5. What influences may bear on, or constrain older residents' ability to maintain their independence and dignity within the care home setting?
6. What are nursing home staffs' perceptions of their own beliefs, behaviour, compassion and dialogue in their job role, and to what extent do they believe these are important?
7. To what extent do power differentials exist in the relationship between nursing home residents and staff and how does this impact on nursing home care delivery?

## **Chapter 1: Contextual Review**

This, contextual review has been iteratively developed over the ten-year lifespan of this thesis (2010 to 2020). Building on the issues described in the introduction it focuses on the wider socioeconomic, political and legislative influences on the evolution and delivery of private sector nursing home care in England since the 1990's. Within this wider context a critical review outlines how groups of care givers (such as nurses, care staff and family members), shape the quality of care provided, and how this may affect older peoples' experience of care, including those living in nursing homes. Other potential causes and perpetuation of inappropriate care in nursing homes, and research-based interventions aimed at addressing this issue is also critically discussed in relation to existing theory and models of care for older people living in this context.

### **Search inclusion and exclusion criteria:**

Searches included literature in the PhD researcher discipline of Psychology and Health Psychology, and also in allied Health Professions related to older people's Health and Social Care, such as Gerontology and Nursing. As the subject of the doctoral research is 'care' within an applied health and social care setting, in addition to peer reviewed academic papers the search conducted also included 'grey' literature such as legislation, and Health and Social Care-related policy and practice documents. Literature outside the UK published prior to 1990 was mostly excluded as the focus of the PhD is nursing home care in the UK that only became prevalent in the 1990's. Literature prior to 1990 that is included comprises mainly of theory-based literature or legislation that was still applicable at the time of writing the thesis.

Search engines used included Scopus, Cinnahl, Web of Science, PsycInfo; and Google Scholar. A first level search was conducted (see table 1 example search terms), and where these searchers provided an excess of papers that were not directly relevant to the present research topic, subsequent combined searches were conducted to refine the results. Examples of second level searches would be search number 1A, 1B and 1C combined and named search 1-ABC (Combined), and search numbers 6A, 6B and 6C combined and named search 6-ABC (Combined) etc. Reference lists of the literature reviewed as suitable for inclusion in the contextual review were also used as potential sources of further information on the topic(s) of interest.

**Table 1 - Example search terms relating to nursing home care for people age 65 and over**

Round 1 Search No.	Main search term	Second level search term		
		A	B	C
1	Care and/or	Old*	Elder(*)	Adult(*)
2	Care and/or	dignity	compassion	personhood
3	Care and/or	Theor(*)	Theory	Model(*)
4	Care and/or	legislation	Law	statute
5	Care and/or	Policy	Practice	strategy
6	Care home and/or	nursing	residential	
7	Care home and/or	Old*	Elder(*)	Adult(*)

The initial search terms used during an online literature search included; old\*; nurs\*; care; care home; nursing home; and resident. The search was conducted in the PsychArticles database resulting in 114 articles of which 95 related to nursing homes. Of these: 61 were within gerontology; 6 social work; 14 consumer affairs; 3 ageing and ageing and social journals; 2 nursing; 8 health and social care; and one politics. The search was repeated in the PsychInfo database resulting in 148 publications of which 52 related to nursing homes. Of these: 17 were nursing; 13 were ageing; 8 were qualitative research; 4 were medical; 3 were psychology; 2 were sociology; 2 were healthcare; 1 was humanities/social; 1 was development disabilities; and 1 was occupational therapy. The literature review revealed that the majority of research and literature exploring nursing homes for older people falls within gerontology (74 articles) with only a few studies being carried out within psychology (3 articles). Of the studies conducted in nursing homes (total 147) the majority were found to use a quantitative approach (110 studies) despite the fact that the nursing home is a social environment that lends itself to exploration using a qualitative research approach.

In addition to database literature searches, updates from websites of organisations involved in nursing home care provision were used. These included Government health and social care (e.g., Department of Health, [DHSS]), regulatory bodies (e.g., Care Quality Commission; Local Involvement Networks), third sector (e.g., Age Concern), private sector (e.g., Nursing Home Association), and media (e.g., BBC News and documentaries) websites. Further documentation included information on policy and practice collected at nursing home level during ethnographic observations: for example, nursing home

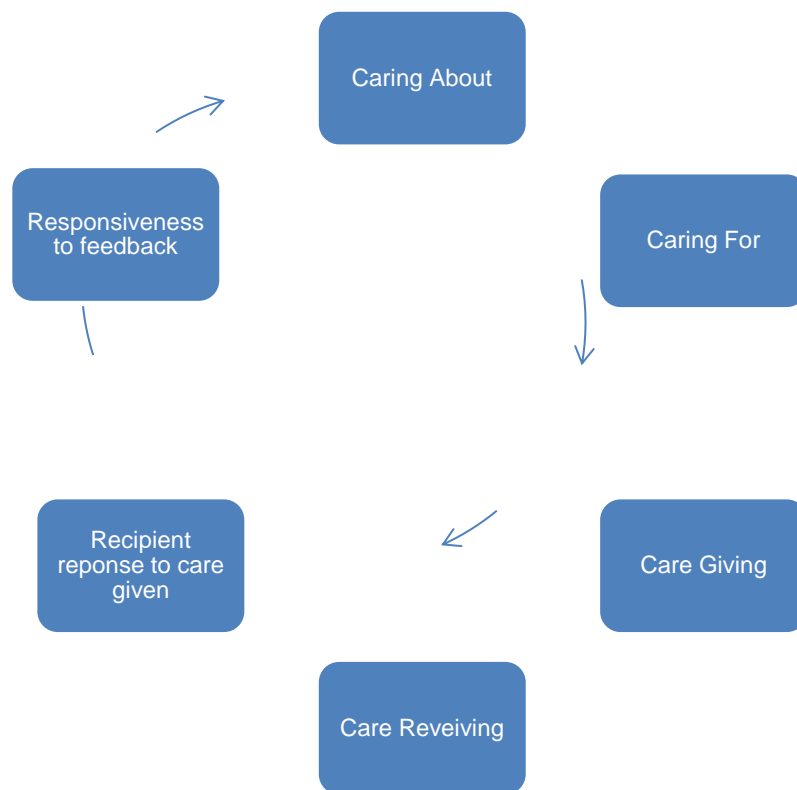
advertising brochures, notices on staff notice boards (prohibition/warnings), whistle blowing policies, training policies, etc.

### Socioeconomic, political and legislative influences on private sector nursing home care delivery in England since the 1990's

The primary aim of the present research is to define 'care' from the perspective of service users and service providers in care homes for older people. According to Collins English Dictionary 'care' is both a noun and a verb: the noun is 'to provide physical needs, help, or comfort' (for), and the verb is 'to have regard, affection, or consideration' (for). In Google, the noun is referred to as 'the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something'. The verb is first 'feeling concern or interest; attaching importance to something' and second, 'looking after and providing for the needs of' someone or something'. Care-giving is value laden due to inherent ethical and moral aspects.

Within feminist literature Joan Tronto's seminal paper 'An Ethic of care' (Tronto, 1993;1998), outlined not only the ethical principles that influence care in Western culture but also the moral aspects of everyday judgements involved in activities of caring for ourselves and others (see figure 1). Tronto (1993;1998) outlines four phases of care. Firstly, '*caring about*' that involves awareness of and attention to articulated care needs. Secondly, '*caring for*' that involves taking responsibility for meeting articulated needs. Thirdly, '*care-giving*' that involves the actual material meeting of caring needs, and fourthly '*care receiving*' that involves response by the care recipient to the care given. Care must involve responsiveness to this feedback which again involves awareness and attention (caring about) resulting in a cyclical care process.

**Figure 1: Tronto's Ethic of Care Cycle**



Using Tronto's ethics, care providers must involve care recipients in the decision-making process and be responsive to their participation. In an attempt to hand back power to people in receipt of care and make care accessible (affordable), the Labour government's Draft Legislative Programme (DLP) (2007), led to proposals in the Personal Care at Home Bill (Department of Health, 2009a), that stated free personal care should be delivered regardless of means. This was later introduced in the (Personal Care at Home Act, 2010), and establish the first step towards providing a National Care Service that is simple, fair and affordable for everyone. There has been much debate about how best to deliver and pay for older people's care services in the UK (Beresford, 2010; Cattani & Giuntoli, 2010; Hirsch & Spiers, 2010; Mauger, Deuchars, Sexton & Schehrer, 2010; Terry & Gibson, 2010), and in Europe (Rodrigues & Schmidt, 2010). Tronto (1993:1998) considers that the way we provide care for older



people reflects the value we place upon them in society, which may be reflected in the amount spent on institutional care, which varies between countries. For example, in 2006, 47.4% percent of public long-term care expenditure in the England was dedicated to institutional care compared to 80.4% in Switzerland and 26.2% in Italy, (Rodrigues et al., 2010). Applying this fiscal formula, the English government could be said to value its older care home population twice as much the Italian government, but only half as much as the Swiss government.

Where there are fewer publicly financed services, and less de-familialisation and greater internalisation of social burdens within the family, informal care and family support increase (Bolin, Kindgren & Lundborg, 2008). For example, family delivered care is more prevalent in Mediterranean countries and Germany than in Nordic counties (see Rodrigues, 2010). In Scandanavian countries social-democratic welfare regimes encourage women to take up paid employment, whereas conservative welfare regimes (e.g., Germany and Austria), and countries from the “Latin Rim’ (e.g., Italy, Spain, Greece and Portugal), emphasise the traditional role of the family in care delivery (Jensen, 2008). In contrast, the “Liberal” approach to the delivery of welfare services adopted in the UK and Ireland is largely measured (both in terms of responsibility for, and quantity of, care services), through public expenditure. The aforementioned relatively low investment in institutional care by the UK government compared to other countries reflects the fact that care home provision is primarily provided by the private sector.

Also, the wage differentials between countries result in migrant care workers (referred to as ‘grey market’) providing 24hour home care in societies such as the UK, where adult children have to continue to work for financial reasons, or choose

to work rather than care for older relatives (Betio, Simonazz & Villa, 2006). Currently in England, 5.5% of the 1.2 million workforce and 8% of adult social care workers are European migrants and anticipated restrictions on UK immigration is expected to increase staff shortages thereby impacting negatively on service delivery (McKenna & Baird, 2019). In terms of Tronto's ethic of care, the UK's failure to make adequate provision of social care workers is in breach of the third obligation (*'care-giving'*) that involves the actual material meeting of caring needs.

In terms of material care needs the total cost of care for the UK government was identified by Wittenberg and colleagues (2004), as reaching £12.9 billion in 2000, of which £2.2 billion was for residential care with costs anticipated to increase to at least £53.9 billion at year 2000 prices by 2051 (Hirsch, 2005). Prior to 2003, residents in nursing homes had to pay for nursing care when it was free at the point of delivery in both hospital and community care. This was considered a breach of their human rights and resulted in the government providing 3-tiered funded nursing care for 125,000 eligible residents living in English nursing homes in addition to those already eligible for social care funding (Department of Health [DOH], 2003). In 2007, the 3 tier assessment criteria changed to an assessment for NHS continuing healthcare, ensuring eligible nursing care home residents receive a weekly rate of £100 paid to the nursing home by Health and Social Care to cover nursing costs (NI Direct, 2019). Such investment in material *'care giving'* by the UK government comply with Tronto's ethic of care, and go some way towards reducing inequalities in care delivered for individuals requiring nursing home care compared to those directly accessing NHS care services.

However, due to the global economic crisis since the millennium and austerity measures imposed in the UK by the government (elected to office in 2010), funding cuts to NHSs and Local Authorities result in regional variations in the amount of funding available for health and social care for adults in England. Although expenditure on social care by Local Authorities in England was £22.2 billion in 2018/19, in real terms this was £300 million below that of 2010/11 (The Kings Fund, 2020). On average care home fees in the UK cost £600 per week and nursing home fees £800 per week (Age UK, 2019). Funding towards fees by Local Authorities is means tested and pays a set amount towards fees, which is often less than the fees charged by care home providers. Individuals having capital of £23,250 or more are required to pay for all of their care home fees, and capital of £14,250 or less is ignored in calculating the individual's contribution towards their care (NI Direct, 2019). Insufficient collaborative working and understanding of resident's care needs within social services has also hindered care home managers in the process of obtaining Local Authority funding for residents (Carpenter & Stosz, 2008). Thus, from the perspective of Tronto's ethic of care, the under-investment in care home provision in the UK is indicative of a failure to value its older population.

Such financial constraint has had a negative impact on the quality nursing home care provided: for example, Health and Social Care and private care home providers failing to deliver adequate levels of staff training and basic services e.g., chiropody, optician, and dentist services, and the provision of mobility equipment (Sheffield LINK, 2011). Additionally, a lack funding in the UK has led to low staffing levels and inadequate equipment where *'36% of nursing home staff and 27% of residential staff stated financial pressures had led to providers accepting residents with complex needs that do not fit their category of registration'* (Royal

College of Nursing [RCN], 2010, p2): potentially compromising levels of care. Almost 10 years later the Royal College of Nursing (RCN) continues to report that there is insufficient nursing capacity in care homes to meet demand (RCN, 2019). Again, this highlights the continuing lack of investment in institutional care provision for older people in the UK.

### Commissioning, integration and regulation of Health and Social Care service provision

Government response to calls to improve service planning came with the introduction of the Health Act (1999), that allowed integration of NHS and health related Local Authority services. At the same time National Service Frameworks (NSF's) (DOH, 2001), facilitated integration of commissioned services thus promoting partnership between health and third sector (voluntary) organisations. Under the NHS Plan (Department of Health [DOH] 2000), services previously under the remit of the Local Authority were now co-ordinated jointly with Care Trusts that were established under the Health and Social Care Bill (2000). The remit of Care Trusts included the provision of care based on the needs of the local population, and focused on older people and those with learning disabilities and mental health services. Further initiatives included the introduction of practice-based joint commissioning, addressing issues surrounding older people's care provision (e.g., Department of Health [DOH], 2005). Despite joint commissioning poor integration and communication between public and private care sectors continued, for example, conflict between the priorities of emergency departments and nursing homes resulting in care delivery that is not always in the best interest of residents (McCloskey & den Hoonaard, 2007). This focus by service providers on their own needs rather than those of the care recipient fails to meet all four phases of Tronto's (1993;1998) ethic of care through: lack of

awareness of and attention to the recipients' care needs; a failure to take responsibility for and actually meeting these needs; and insufficient responsiveness to feedback from care recipients on the care delivered.

To improve collaborative service provision, the NHS Five Year Forward View (NHS England, 2014) proposed that NHS providers work in partnership with care home providers and Local Authority services to develop new models of care and support for older people. For example, the use of tele-health links between nurses and consultants providing support and advice to nursing homes both in and out of normal working hours. This initiative reduced emergency hospital admissions from nursing homes in Airedale, England by 35%, and Accident and Emergency attendances by 53% (NHS England, 2014 p16). Despite such local initiatives the number of all people aged over 80 in England presenting in Accident and Emergency rose from around 60,000 in 2013/14 to over 72,000 in 2017/18: an increase of 20% in just four years (Age UK, 2019). This review also identified delayed transfers for older people into services across many National Health and Social Care Services, with access to residential and nursing care placements among the worst hit (Age UK 2019, P56). Overall, initiatives in the UK to improve the commissioning and delivery of care services for older people living in care homes fails meet the ethical criteria laid down by Tronto in the 1990's.

In addition to implementing joint commissioning interventions to improve Health and Social Care service provision in England, the government also passed the Health and Social Care Bill (2008). As of 2010, this bill combined Health and Social Care regulators into a single regulatory body called the Care Quality Commission that monitors and enforces existing National Minimum Standards

(2002) of care in independent sector care homes for older people. The restructuring proposed changes in the way nursing homes were inspected and assessed, and included the transfer of much of the responsibility for 'on site' care home inspections to Local Authorities and local NHS Trusts. In turn they disseminate information to the Care Quality Commission: effectively reducing duplication of site inspections and paper work. This was generally perceived as a streamlining and cost-savings exercise that met with criticism from both consumer organisations and service commissioners themselves due to reports of poor care standards in community, acute, and long-term care institutions, and a lack of response to complaints about these services. Consequently, the Care Quality Commission policies were reviewed and its regulatory powers extended to intercept and instruct the rectification of poor practice. However, Care Quality Commission inspections were only conducted at night upon receiving a complaint, and were less thorough than during the day (Kerr et. al., 2008). Despite night staff being found to have less relevant training, to be isolated/anxious due to lack of management and supervision, and have greater supervisory responsibilities for agency workers, standardised night-time inspections that were recommended by Kerr in 2008, were still not conducted in the UK in 2020. By omitting night time inspections the Care Quality Commission fails to assess the quality of 34% of the daily care delivered in nursing homes in England. Despite such shortfalls, the Care Quality Commission is compliant with Tronto's requirements for ethical care provision in so far as it considers the views of care recipients in its reporting, and makes service providers accountable for the care they deliver and responsive to any changes required.

## Interventions promoting public and patient involvement in the development and delivery of care services and research

In practice the barriers to the delivery of the initiatives outlined above were extensive. These included a lack of transparency and honesty by commissioners, restrictive technical and procedural issues that inhibited the transfer of power and ownership to service users, a lack of involvement in and education of service users about procedures throughout the decision-making process, and the need to value service user contributions (Mauger et al., 2010). Other solutions to integrating care design and delivery were then proposed taking into consideration the following five areas. First, client perceptions of the accessibility of care and support (e.g., Cattan et al., 2010); second, guidance on compliance with the Health and Social Care Bill (2008) regarding service-user involvement (CQC, 2009); third, tools to enhance demand forecasting and capacity planning (e.g., CSED, 2007); fourth, strategies for early intervention and prevention of inadequate services for older people (e.g., Institute of Public Care [IPC], 2010); and fifth, ways to integrate service delivery and infrastructure (e.g., Porteus & Spence, 2010). These were the first real initiatives to involve service users in the delivery of care services.

The shift to increase public involvement and integration within care service delivery came with the NHS Reform White paper (Department of Health [DOH], 2010) introduced by the then coalition government. The paper completely reconfigured the infrastructure of Health and Social Care services by dissolving Care Trusts and making General Practitioners responsible for the commissioning of health care services. Soon after, the Health and Social Care Act (2012) provided patients the opportunity to choose services to meet their individual needs; delivered patient advocate 'Healthwatch' organisations locally and

nationally to drive patient involvement across the NHS; introduced the foundations of the new body Public Health England to promote improvements in the public's health; and made Local Authorities responsible for joined-up services locally.

Despite initiatives to commission, deliver and regulate care services for older people, it has been suggested that historically chronically mentally ill individuals within Western cultures including the UK, are treated as an underclass that are undervalued and ignored (Levine, 1979), and that the quality of public care institutions and public policy in relation to dependent groups reflect the social and economic values of the times (Williams, Bellis & Wellington, 1980). Others argue that until society itself begins to value and champion the qualities of, and give voice to, the needs of its vulnerable there will be little improvement in care provision for older people and other marginalised groups (e.g., Shadish, 1989: Tronto, 1993;98). Yet vulnerable older people living in 21<sup>st</sup> century Britain, including those with chronic mental illness such as dementia, are still experiencing discrimination in the provision of Health and Social Care services. For example, financial and physical abuse, neglect, and a lack of autonomy and choice were found in homecare services for older people (Equality and Equal Rights Commission, 2011).

Ways to nurture a collective voice of care consumers have been suggested including: the need for service providers and health professionals to acknowledge client personhood (Clare & Cox, 2003). Others propose that for care workers to uphold clients' personhood, the personhood of care workers themselves must also be upheld within the context of the care relationship (Kadri, Rapaport, Livingston, Cooper et al., 2018). Brendan McCormack (2004) views personhood



as human ability to engage in second-order reflective evaluation of action, and the individual's freedom of will guided by an intrinsic moral compass that gives status to persons, regardless of impairment. This builds on Tom Kitwood's definition of person-centredness that acknowledged both the individual and their context suggesting it is '*a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being: It implies recognition, respect and trust*' (Kitwood, 1997, p8). Kitwood's (1997) person-centred care model considers personhood to be central to good care-giving and remains integral to Kitwood's theoretical template for delivering person-centred care for people with dementia (Mitchell & Agnelli, 2015). The personhood and wellbeing of an individual is enhanced through recognition, respect and trust and is referred to by Kitwood as '*positive person work*', whereas the opposite undermines the person's wellbeing and is referred to as '*malignant social psychology*' (see table 2).

Kitwood's person-centred concepts form the basis of a model of care for people with dementia developed from the Bradford Dementia Group (Brooker, 2004) and subsequently used in nursing homes (Rosvik, Brooker, Mjourn, & Kirkevold, 2013). The model is represented by the acronym VIPS: the model '**V**alues' '**I**ndividuals' and their '**P**erspective' within a positive '**S**ocial environment'. It requires that everyone involved in the delivery of care including organisations, formal care givers and family members, must have the skills to provide a positive social environment for people experiencing dementia. Indeed, this is supported where positive person work by care workers in care homes for older people was found to improve the wellbeing and physical outcomes of residents with dementia, whereas interactions aligned with malignant social psychology undermined resident's personhood (Mitchel et al., 2015).

**Table 2: Concepts of person-centred care developed by Kitwood (1997)**

<b>Malignant Social Psychology</b>	<b>Positive Person Work</b>
Treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment, objectification, ignoring, imposition, withholding, accusation, disruption, mockery, disparagement	Recognition, negotiation, collaboration, play, giving, stimulation, celebration, relaxation, validation, holding, creation, facilitation

Although the NHS adopted Kitwood's theory of person-centred care, the framework prioritised the individual (Department of Health [DOH], 2001). This individual patient-centred model has been criticised for failing to acknowledge the role of context, care-givers, and other stakeholders in the delivery of care (e.g., Clare & Cox, 2003; McCormack, 2004; Nolan, Brown, Davies, Nolan & Keady, 2006). Also criticised is the NHS's institutional failure to promote trust in the care recipient /care-giver relationship (e.g., Brown, 2008). Nolan also suggested that the emphasis on the individual in person-centred care in gerontology practice (Nolan, 2001) and care policy (e.g., Department of Health [DOH], 2001) failed to acknowledge the relational, social, and contextual aspects of person-centred care that are needed to uphold personhood (Nolan, Davies, Brown, Keady &

Nolan, 2004). The Senses Framework that was first published in 1997 (Nolan, 1997) incorporates these broader aspects of care, and has since been developed through research applying its principals in a number of care contexts for older people (Davies, 2001; and Nolan, et al., 2006).

The Senses Framework (Nolan, 2004) encompasses both subjective and perceptual dimensions of caring relationships as well as the interpersonal processes and intrapersonal experiences of giving and receiving care (see figure 2). Integral in the framework is that those involved in care (both giving and receiving) should experience relationships that promote the six 'senses' of: security; belonging; continuity; purpose; achievement; and significance. The Senses Framework was developed for care in longer term institutional settings where 'senses' were found to be relevant for both older people and staff, and instilled a renewed sense of staff job satisfaction that had been suppressed by the NHS blame culture (Nolan, Davie, Brown, Keady & Nolan., 2002). The Senses Framework has since demonstrated the potential to address both individual and shared experiences for care-givers and care recipients in older people's long-term institutional care settings (e.g., Brown-Wilson, Swarbrick, Pilling & Keady, 2012; Nolan, Davies, Brown, Keady & Nolan, 2006; and Ryan, Nolan, Reid, & Enderby, 2008).

Instead of person-centred care, the term relationship-centred care has been suggested to be more appropriate in the care of older people (Nolan, 2004). This is supported where relationships between nurses and older people were found to be central to successful person-centred care outcomes (e.g., McCormack, 2003; Nolan, et. al., 2004). Subsequently there has been an increase in the development of models of care within nursing and gerontology

that focus on relationships and the wider context in addition to the individual's needs (McCormack, 2003; McCormack, 2004; McCormack & McCance, 2006; McCormack, Dewing, & McCance., 2011; and Nolan 2004). The rationale for combining the Senses Framework with relationship-centred care is to enable interactions that promote the senses through a sense of connectedness (see Nolan, 2006).

**Figure 2: Nolan's Senses Framework**

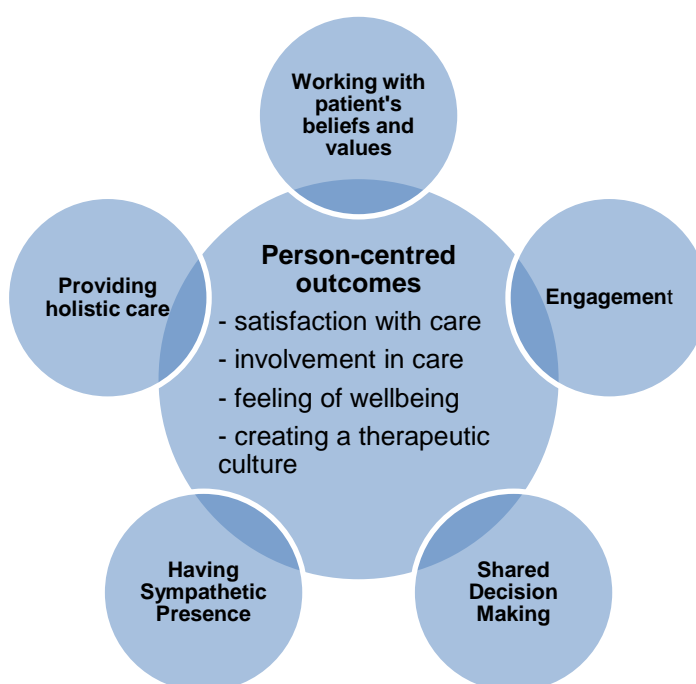


Source: Getting Research into Practice (GRiP) Report No 2., Nolan, M. R., Brown, J., Davies, S., Nolan, J. and Keady, J. Sheffield Hallam University Research Archive

However, models that are by name 'person-centred' (e.g., McCormack, et. al., 2011; and Kitwood, 1997), are also supported as having consideration for relational aspects of care (e.g., Dewing, 2004; and Mitchel et al., 2015). They suggest the humanistic nature of care legitimises the use of the term person-centred rather than patient-centred care (McCormack et. al., 2011).

McCormack's person-centred nursing framework was originally tested in an acute setting (McCormack et al., 2006; and McCormack et. al., 2010) (see figure 3) and then successfully applied in a mixed methods participatory research study of nursing care practice in various older people's settings in Ireland (McCormack, 2011).

**Figure 3: Person-centred nursing framework (McCormack and McCance, 2006)**



McCormack's person-centred nursing framework takes into consideration the wider environment in which care is delivered (including the institution's culture, policy, and practice), acknowledging relationships between care givers and care recipients, and the attitudes and beliefs of staff and care recipients.

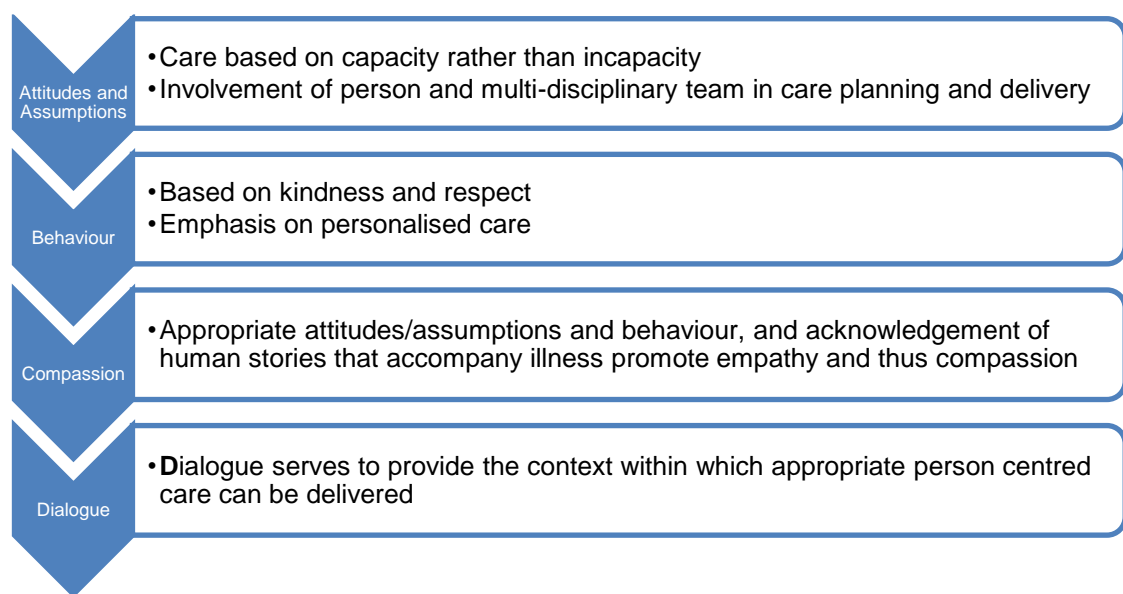
Additionally, despite the emphasis on dignity conservation in relation to quality care-giving, there is no agreed definition of the concept of dignity. A review of the literature relating to dignity in health suggests it comprises of two main concepts namely human dignity and social dignity (Jacobson, 2007). *Human*

*dignity* refers to the moral and rational capacity of humans to treat people with respect, and social dignity relates to both dignity-of-self (e.g., self-respect, self-confidence) and dignity-in-relation (impact of the reflected reactions of external others on the individual's sense of self-worth). Jacobson (2009) subsequent taxonomy of dignity provides: language by which to understand dignity (based on the concepts of human dignity and social dignity); the mechanisms in which dignity may be violated and promoted; and a map of potential dignity-promoting interventions. A qualitative review of dignity from the perspective of nurses and older patients proposed a model that suggests dignity is relational, and that the communication, working culture and environment all be taken into consideration (Sanakova & Cap, 2019). The relational nature of *social dignity* means it can be compromised, which is evident where dignity of older people continues to be undermined in health care settings (e.g., Francis Report, 2013). However, this also means social dignity can be promoted.

Indeed, self-perception has been found to be a mediator in dignity and is key to maintaining a sense of wellbeing: for example, during illness (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov, 2004; and Chochinov, 2005), and among older people living in care homes (Hall, Longurst, & Higginson, 2009). When an individual's sense of personhood is not acknowledged, patients are more likely to feel they are not being treated with dignity and respect (Wilson, Curran, & McPherson, 2005). It may also undermine patients' (Chochinov et al., 2002) sense of value or worth resulting in an increased feeling of being a burden to others, leading further to a reduced sense of purpose in life (McPherson, Wilson & Murray, 2007). This finding provides the basis of the dignity conserving care model (Chochinov, 2007) (see figure 4). The key principles of dignity conserving care are summarised by the mnemonic 'A, B,

C and D’ and are designed to “remind practitioners about the importance of caring for as well as caring about their patients” (Chochinov, 2007, p185); ‘A’ represents attitudes and assumptions, ‘B’ behaviours, ‘C’ compassion’, and ‘D’ dialogue. The model was found to enable care providers to assert positive self-perception in older people living in institutional care homes and helped residents retain their sense of dignity at a time when they felt most vulnerable (Hall et al, 2009).

**Figure 4: Chochinov’s Dignity Conserving Care model: A,B,C and D**



More recently, action research was conducted in English care homes to evaluate a toolkit developed to preserve dignity (The ENACT Project: Gallagher, Curtis, Dunn & Baillie, 2017). The research found: ethical leadership is key to creating space for discussion about dignity between staff and residents and/or their relatives; action research support the development of a resource that provide care-home specific ways to deliver dignified care; and participation in action research empowers care givers and care recipients, increases staff enthusiasm, and promotes partnership and a sense of being valued (Gallagher et al., 2017). Thus, Chochinov’s dignity conserving model and Gallagher’s dignity toolkit are aligned with Tronto’s Ethic of Care principles, and equivalent to

Kitwood's 'positive-person work and McCormack's 'prerequisites' relating to staff competence to deliver care. Additionally, for either to promote dignity all six senses of Nolan's model must first be experienced by care givers and care recipients.

Despite these models and tools in the delivery of care, others still caution the need to overcome the systemic paternalism inherent in Health and Social Care services (Richards, Coulter & Wicks, 2015). In the UK irrespective of the development of models of care and the promotion of social inclusion to promote equality of access to care resources through legislation, there is still the danger of inadequate involvement of older people and their family in care decisions: especially for those with marginalised or complex needs. This is despite research supporting the ability and desire of older nursing home residents to be involved in decisions about their care, including those with impaired mental capacity (e.g., Hubbard, Downs, & Tester, 2003; Brooker, 2004; Carpenter et. al., 2007; and Gallagher, 2017). In order to determine how effective care home provision is in practice it is important to conduct further research in nursing homes. However, gaining the trust of care providers to engage in research is challenging due to suspicion about scrutiny from outsiders perpetuated by negative perceptions of nursing homes within wider society (Kayser-Jones, 2003). Maintaining positive relationships between researchers and nursing home providers throughout the research process requires developing and maintaining relationships with providers and care recipients through reciprocity, objectivity and empathy; and awareness of appropriate and ethical research activity (Kayser-Jones, 2003).

Other research findings support that it is possible to effectively engage older people in research, including those with physical and cognitive disabilities. For



example, ethnographic nursing home research successfully combined interview techniques with observations that capture the embedded daily living experiences of individual and groups of residents with dementia who were unable to articulate their thoughts and feelings (Hubbard et. al., 2003). Hubbard's study found it necessary for researchers to be sensitive to the emotional, cognitive, physical, and verbal responses of individual participants with dementia, and based on these observations to be flexible in their approach to data collection: for example, if nursing home residents become agitated while being interviewed switch to less restrictive methods such as observation. Such methods provide the opportunity for researchers to engage with participants, and have been described as 'meaning-making occasions' that are mediated by social cultures (Gubrium, 1995). Indeed, this flexible approach to data collection is adopted in the present thesis.

Also, ethnography and photographs are methods used in the present thesis. This method has been successfully adapted in nursing homes as a tool to qualitatively explore residents' perceptions of care home living, and how the design of the care home environment impacts on residents' life-world and quality of life (Craig, 2017). Another study effectively used focus groups to establish what was considered meaningful activity in people with dementia living in care homes (Harmer & Orrell, 2008). It found that residents had different priorities to family members and carers, where residents valued activities that addressed their psychological and social needs, whereas family members and carers viewed activities that maintain physical abilities as important. The fact that resident's needs are not always understood by family members and carers is supported where some spouses of people with dementia were found to have unreliable understandings of their partners, and where dementia status in isolation was

insufficient grounds to presume the care recipient's unreliability or poor knowledge (Carpenter, et. al., 2007).

Further research found that staff tend to adopt a paternalistic albeit benevolent perspective inherent in the power endowed on them by the care system and the vulnerable status of residents, which is evident where nurses and carers effectively make decisions about resident's life choices by telling them what they want rather than consulting them (Tuckett, 2006). Even where care staff attempt to include residents with learning disabilities in decisions about care through involving them in group meetings, research found that care staff continued to instruct residents rather than empower them, thus directly contravening official institutional policy (Antaki, Finlay & Walton, 2007). It was also found that the preferences and beliefs of older people with or without cognitive impairments changed over time suggesting regular assessment of care needs should be undertaken (Carpenter, 2007). Such findings emphasise the importance of establishing the viewpoint of care consumers with dementia when planning care as their priorities may differ markedly from those who consider themselves advocates, and those who deliver care.

Additionally, in order to promote inclusion of those with dementia in decisions about care, the Dementia Strategy implementation plan (Department of Health [DOH], 2009b) highlighted the need for better training and education for professionals to detect and understand dementia and provide integrated multi-disciplinary care and support for people living with dementia in the community. The Care Quality Commission also revealed the need for dementia awareness training for staff working in institutional care settings including hospitals (CQC, 2011a). In nursing homes, managers also expressed concerns about a lack of

dementia-specific modules on the National Vocational Qualification or Skills for Care training delivered in care homes (Conroy, 2006). In response, and as a result of findings, strategies for delivering care in the UK for nursing home residents experiencing dementia were developed i.e., the Dementia Audit Tool that reviews assessment and care planning, prioritises staff training, and builds on best practice (Conroy, 2006; 2008). In addition to deficits in staff training, Conroy (2006) also reported that some staff felt frightened to work with people with dementia.

Despite staff expressing fear of working with people with dementia, the care giver is in the position of greater power due to the vulnerable (dependent) position of the older person, and such power structures shape the respondent's experiences (Nicolson, 2001). For example, unsuccessful interactions between care staff and nursing home residents during mealtimes have been found to negatively impact on the quality of life of older adults experiencing dementia (e.g., Pierson, 1999; Dunn et al., 2014). Also, as outlined in the introduction, there have been repeated instances of convictions of care staff for abuse of older people with or without mental incapacity living in nursing homes (e.g., BBC News, April, 2014; CQC, 2014a; CQC March, 2015; CQC January, 2019). These instances of abuse existed even though Care Quality Commission inspections found nursing homes had used evidence-based tools for assessing and monitoring older resident's care needs, and had provided staff with appropriate training in their use. As National Minimum Standards (NMS's) of staff training are often met in care services that have been found to deliver poor care, this suggests issues other than staff training may influence poor care practice. Indeed, the Care Quality Commission Chair Dame Jo Williams (Campbell & Meikle, 2011), emphasised the need to deliver person-centred care based on kindness and

compassion rather than task-focused care that was found in the Care Quality Commission's (2011a) damning report of hospital care for older people. This statement suggested that the existing rationalised model of care delivery and the negative attitudes and behaviours of NHS care workers had contributed to poor care delivery: thus, acknowledging institutional, embodied, and relational influences on care provision. Such findings support the need for a clear model of care for older people living in institutional care that embodies all these elements. Arguably Tronto's ethic of care, Kitwood's concepts of person-centred care, and the principles of Chochinov's dignity conserving care model run through both Nolan's Senses Framework and McCormack's Person-centred Nursing Framework, which both equally encompass institutional, embodied and relational aspects of care delivery. As such, either model is considered appropriate in the nursing home context.

#### Influences on the quality of the Health Professional - care recipient relationship

The Health Professional's relationship with older people has its own challenges particularly among people aged 85 as they are more likely to have cognitive impairments, poorer physical health, fewer financial and social resources, and less consumer advocacy awareness (Hauge & Ory, 1987). However, the older person's experience of care service provision can also be negatively affected by poor attitudes of the Health Professional. In the nursing home environment, the relationship between staff, residents, and their families was found to be pivotal to resident's life experiences, and how carers communicated with residents influenced how residents felt (Davies & Brown Wilson, 2007). Inflexible routines and staff's inadvertent restriction of resident choices reduced the autonomy of frail older residents, especially those with

cognitive impairments who may find it difficult to communicate their wishes (Davies et al., 2007; Dunn, 2014).

From a positive perspective, older residents (including those experiencing dementia) were found to respond to staff reporting high levels of job satisfaction, and those who showed an interest in them (e.g., Bergener, Jirovec, Murrell & Barton, 1992; Chou, Boldy, & Lee, 2001; Gallagher, 2017). Conversely, poor Health Professional communication, attitudes and behaviours lead to negative outcomes such as behavioural disturbances and poorer health and emotional outcomes. For example, patient's perceived feelings and thoughts from staff were found to correlate significantly with staff expressed feelings indicating that patients were sensitive to and reacted to staff feelings for them (Barrowclough et al., 2001). Also, poor levels of staff interaction with care recipients resulted in detachment and withdrawal in nursing home residents, whereas the presence of staff and positive staff interaction increased activity and observable displays of pleasure and happiness (Clark & Bowling, 1990). Clarke also found that a quarter of staff interactions in participating nursing homes resulted in demeaning practices such as ignoring resident's requests for help. This along with the aforementioned models of 'care' and 'dignity' highlight the need to promote greater staff interaction in order to increase the level of engagement in activity, sense of pleasure, and happiness of nursing home residents.

Un-successful interactions during mealtimes have also been shown to negatively impact on the quality of life of older adults living with dementia (Pierson, 1999), and to negatively influence the nutritional status of nursing home residents (Kofod & Birkemose, 2004). Conversely, positive interactions between staff and residents in more social environments (e.g., encouraging residents to

decide on menu content, engage in meal preparation, and influence daily routines) were found to improve the nutritional status of residents whose Body Mass Index (BMI) indicated under-nutrition (Kofod et al., 2004). This demonstrates that positive interactions between care givers and care recipients have a positive influence on physical health outcomes as well as the psychosocial wellbeing of older people experiencing dementia.

In addition to poor interactions with care workers, care practices such as routine working also have a negative impact on the wellbeing of nursing home residents. For example, a culture of routine arbitrary checking of residents throughout the night, along with unacceptable levels of noise led to disturbed sleep, and caused agitation in nursing home residents (Kerr, 2008). Such disturbed sleep at night impacted negatively on the ability of residents to engage positively in activities during the day, and lead to a disruption of the normal sleep pattern (Flick, et al., 2010). Following Kerr's (2008) study, recommendations for good practice included: night-time regulatory checks as standard; improved communication systems between managers/night staff and with relatives; access to necessary equipment and training for night staff; silent night-time call systems; minimal use of agency and bank staff; introduction of named key night-time care worker for each resident; and personalised night-time care plans for each resident. Despite these findings evidence of Kerr's recommendations being applied in practice are not forthcoming.

. Another concern is that many nursing home residents have physical impairments, medical conditions, depressive symptoms and have been exposed to stressful life events, all of which have been identified as risk factors for suicide in this environment (Nelson & Farebrow, 1980; Reiss & Tishler, 2008[a]; and Simmons et al., 2004). Research found that problems in interpersonal

relationships increased the risk of depression, whereas close human bonds protected against depression (Klerman, Weissman, Rounsaville, & Chevron, 1984), including depression experienced in late-life (Hinrichsen, 2008; 2010; and Hinrichsen & Emery, 2005). Depression among people in UK residential care has been found to be between 15-25% (McCabe, Davison, Mellor & George, 2009), which is of concern due to its links with suicide rates. These rates were considered to be an underestimate, exacerbated by findings of insufficient training of Health Professionals in recognising depression in older care recipients (McCabe et. al., 2009), and compounded by under-treatment of older nursing home residents displaying signs of depression due to inappropriate referral by nursing staff (Brown, McAvay, Raue, Moses & Bruce, 2003). A further barrier to referral of residents for treatment for depression was staff's attitude that depressive symptoms are a normal reaction to loss, bereavement or ill health, and an acceptable consequence of ageing (Bagley et al., 2000). Additionally, professional carers may lack the ability to communicate older people's needs for other care such as acute Accident and Emergency care (McCloskey et al., 2007). To compound the issue General Practitioners have been found to dismiss nursing home care provider's concerns, highlighting the need to enhance communication skills between different service providers and Health Professional disciplines (Brown et al., 2004).

One reason for such breakdown in communication between Health Professionals and care recipients may be due to high levels of stress that prevail among staff caring for older people (McCabe et al., 2009). Findings suggest that there is a lack of time available for staff training to meet the cognitive and emotional needs of elderly care recipients (Baillon, Scothern, Neville, & Boyle, 2006). Insufficient and/or inappropriate training and high levels of stress may

result in staff developing negative attitudes towards residents with depression, and inhibit the quality of care delivered by nursing staff and Care Assistants (Brodaty, Draper, & Low, 2003). This is exacerbated by a reluctance of older people to express their mental health problems due to stigma (Lyness et al., 1995). Research also found an emphasis on the physical care of older care recipients at the expense of psychological aspects of care thereby inhibiting the detection and treatment of depression in older care recipients (McCabe et al., 2009). This was manifest by negative attitudes among carers, a lack of appropriate staff training in the detection of depression, and the disinclination of older people to talk about their depression (McCabe, 2009).

Equally there is insufficient training on the detection of suicidal thoughts or behaviours in residents for either nursing home staff (Teresi, Abrams, Holmes, Ramirex, & Eimicke, 2001), or for psychologists (Reiss & Tishler, 2008 [b]). In contrast to the general population, nursing home residents are unlikely to display “active” suicidal behaviour such as taking an overdose, mainly due to the inherent environmental safeguards e.g., few nursing home residents self-medicate. Instead, self-harm may be displayed through indirect self-destructive behaviour or passive suicide over time, such as refusal of diet or medications, unwillingness to get out of bed, excessive drinking, or taking unnecessary risks (Conn & Kaye, 2007). Although in many cases this behaviour has been attributed to dementia rather than suicidal tendencies, staff should be alert to such behaviours and ensure additional assessment and follow-up e.g., screening for depression. Additionally, suicide rates for residents have been found to be more problematic in nursing homes that are large, have high staff turnover, and resident autonomy is limited (Osgood, 1992), or where residents express dissatisfaction with care or treatment (Jongenelis et al., 2004). This suggests the relationship residents have



with staff may influence residents' inclination towards suicide, where short-term and less intimate relationships result in more negative outcomes for residents.

#### Carer-resident relationship – negative outcomes for care staff and subsequent care delivery

In addition to negative impacts of a poor relationship with care staff on resident wellbeing, there are also potential adverse outcomes for health care workers. The psychosocial dynamics and complexity of the carer - resident relationship is a difficult one for carers to cope with due to factors such as resident dependency (Nicolson, 2001), and relatives' projection of their guilt feelings in the form of dissatisfaction with the service delivered (Gaugler, Hepburn, Mittleman, & Newcomer, 2009). Indeed, research indicates that Health Professionals are in need of more psychosocial training given the increasing psychosocial demands of patient care (e.g., Maben, Cornwell & Sweeney, 2010), which arguably may facilitate an improvement in the quality of care delivered, as well as a reduction in staff absenteeism and sickness rates. These findings are supported by the author's own research exploring the barriers to enhancing residents' dining experiences from the Care Assistant's perspective (Dunn, 2014). Findings revealed that nursing home Care Assistants' positive talk about older adults was juxtaposed against their accounts of caring, which were more aligned with the medical model than a psychosocial model of care, and served to de-legitimise residents' autonomy. Staff shortages, highly routine work schedules, physical demands, and 'difficult' residents emerged as barriers to facilitating positive social dining experiences for residents.

In order to protect themselves from the more emotive aspects of their work, Health Professionals tend to detach themselves from these distressing aspects of their job. Such behaviour has been found in nursing homes where carer's

detachment of themselves from residents was identified in the form of 'labelling' and 'stereotyping' of residents (Dunn, 2014). This supported research suggesting that patient centeredness may be resisted by Health Professionals and perceived as a further demand (Fulton, 1996). Detachment is evident in staff experiencing occupational stress (Cohen-Mansfield, 1995), and provides Care Assistants with a buffer from the stressors associated with caring and death of vulnerable older adults, such as resident suicide (Teresi et al., 2001). Such instances of sudden or traumatic death of care recipients potentially result in carers experiencing complicated grief (Holland, Currier, & Gallagher-Thompson, 2009) or 'syndromal' depression (Zhang *et al.*, 2008).

The ability of carers to negotiate the stress associated with their role is a major issue for employers due to staff absenteeism, e.g., in the NHS staff sickness was identified as being highest amongst Health Care Assistants (6.9%) when compared to other care deliverers (NHS Information Centre, 2010). Similarly, staff absenteeism in nursing homes for older people was found to impact negatively on the delivery of overall person-centred care (Dunn, 2014). Other research suggests staff shortages also impaired the quality of nursing home care delivered at night due to dependency on unfamiliar agency and bank staff, which also increased the workload of regular staff (Kerr, 2008).

A review of occupational stress models and an alternative theoretical model of long-term nursing care stress suggests a basis for the conduct of research on staff stress in the nursing home environment (Cohen-Mansfield, 1995). The model included factors that influence nursing home staff's levels of stress that were condensed into the manageable concepts of **Entity** (attributes under the control of the workplace), **Needs** (variables that the individual looks to have

satisfied in the workplace), and **R**esources (variables that allow the individual to cope with the workplace where staff's expectations of it are not met). Their responses are divided into **P**hysiological (e.g., symptoms such as fatigue, physical exhaustion, frequent headaches and colds), **C**ognitive (e.g., distancing, appraisal of burden, optimism, disillusionment), **E**mootional (hope or confusion, exhaustion, cynicism, depression, hopelessness), and **B**ehavioural components (e.g., job performance and social relations, coping skills such as relaxation and exercise, quitting job). Cohen-Mansfield (1995) found that high staff occupational stress may result in staff burnout and was related poor quality person-job fit, lengthy duration of stress, and the employee's sense of a lack of predictability and control over it. In reality person-related and job-related variables never fit perfectly and always result in stress. Small discrepancies can be adaptive producing optimal levels of staff performance whereas larger differences may result in occupational stress (Cohen-Mansfield and Wirtz, 2009). An alternative theory is that stress adopts either a positive or negative value dependent on the recipient's perception of it (Lazarus, Cohen, & Folkman, 1980; Lazarus, DeLongis, Folkman & Gruen, 1985), which suggests a combination of expectations and experiences are implicated in the production of occupational stress.

One study found that care staff who worked on permanent assignment in nursing homes expressed greater job satisfaction and lower levels of staff turnover than care staff on rotating assignments, although they had higher levels of absenteeism (Burgio et al., 2004). Unexpectedly the same study found no differences in the quality of care delivered between permanent and rotating staffing assignments. This may be due to residents only being paired to their permanent staff carer on half of the days recorded in the study, thus reducing the

ability of permanent staff to build strong relationships with residents. Further, during evening shifts residents' behaviour was found to be disengaged and more disruptive (Burgio, 2004), which combined with the working unsocial evening hours may account for the fact that staff turnover was greatest in staff working evening shifts. However, there was higher burnout and absenteeism in staff working morning shifts, which Burgio (2004) attributed to the physical nature of the work.

Other research found that where nursing home staffs consider the quality of care to be high, they have higher job satisfaction in relation to three domains: pay, management and work (Castle, Degenholtz & Rosen, 2006). As job satisfaction is related to turnover rates, they also suggest that nursing homes that enhance care quality may improve staff job satisfaction and reduce turnover rates (Castle et al., 2006). Castle and colleagues (2006), also found fulltime workers are less satisfied with pay but more satisfied with work than part-time staff, and that Care Assistants were generally more dissatisfied with pay than nurses, supporting previous findings of dissatisfaction with nursing home remuneration rates (e.g., Coward et al, 1995; Harris-Kojetin, Lipson, Fielding, Kiefer, & Stone, 2004). Concerns about inadequate pay and working conditions for staff engaged in home care provision for older people has also been highlighted in the UK (Equality and Equal Rights Commission, 2011). Such cumulative pressures can result in burnout, yet job design and organisational characteristics can be modified to reduce staff stress. By using a specifically tailored measure of nursing home Care Assistant's job satisfaction, it may be possible for employers to predict the extent of staff discontent and take appropriate action to remedy this and reduce staff turnover (Castle, 2010).

High turnover in the UK may also be attributed to the fact that many care workers are recruited internationally, are from diverse ethnicities, and may be subject to exploitation by employers (Leutz, 2010-11), and racial abuse from residents (Berdes & Eckert, 2007). A summary of literature suggested that a number of strategies may be adopted by carers in order to provide effective care while exposed to racial abuse from residents (Berdes et. al., 2007). Firstly, they may draw on care as a source of meaning that re-enforces their self-image as caring beings (Altschuler, 2001). Secondly carers may adopt emotional labour (MacRae, 1998), whereby carer's take on emotional labour rules that are determined by the organisation (Hochschild, 1983). However, this may lead to burnout where carers must act out of character to adopt this stance, or alternatively may result in care that strives to control residents where carers fail to detach their own emotions from the emotional labour rules of the organisation (Treweek, 1996; 2000). Thirdly carers may engage in boundary work (Gieryn, 1983, 1995, 1999) where individuals or groups are distinguished from a particular social category thus excusing them from inappropriate behaviours. Boundary work existed where residents physically abused nursing home care staff, and where staff interpreted this as non-violent as older people were considered to fall outside of societal norms for violence (due to residents' fear of death, homesickness, or lifelong aggressive tendencies) (Akerström, 2002). Berdes and Eckert (2007) also found that carers use the metaphor of family and attachment to express their engagement in the active process of care and to create a personal standard of care, which that they attempt to replicate in their work environment. It is suggested attachment and personal care standards form the basis of effective care onto which high quality technical care can then be built (Berdes et. al, 2007).

However, it is still necessary to understand all potential influences on why care workers may behave in an uncaring manner. Indeed, it has been suggested that despite nurse's initial altruistic tendencies (Lowenstein, 2008), the process of nurse training itself leads to a decline in capacity for expressive care and compassion (Murphy, Jones, Edwards, James & Mayer, 2009). High sickness and absenteeism rates may be associated with the psychosocial demands of the carer role manifest through burnout that has been identified extensively in health care workers. Burnout has been described to be the result of a loss of spirit in otherwise motivated and committed individuals, and from an existential perspective lies in people's need to believe that their lives are meaningful and the things they do are useful and important (Pines, 2002). Due to the conflict between their ideals of 'holistic' care and the reality of 'routine-based' practice, nurses report some degree of burn out within two years of qualification manifest by changing jobs or leaving the profession for good (Maben, Latter & Macleod-Clark, 2007). Research suggests that group discussions, critical incident stress debriefings, giving staff more input into how their job is performed and autonomy in the workplace reduce the likelihood of care staff burnout (Felton, 1998). Other interventions include flexible working, carer involvement in decision making and care planning, and employee training to improve communication between Care Assistants and nurses: this study found that nursing homes that involved Care Assistants in care planning had lower care staff turnover (Banaszak-Holl & Hines, 1996). Using a psychoanalytic-existential approach Pines (2002) was successful in the treating burnout in people from three occupations including nursing. However, the practical and financial implications of such interventions are prohibitive and such proposals do not address the macro (cultural, social, economic and political) influences on staff stress beyond the organisational level.

## Methodological approaches adopted in nursing home care research

Since 1990, when nursing care homes for older people became more prevalent in the UK, there has been little research conducted in this context that addresses the psychosocial dynamics of the carer-resident relationship, how they each negotiate such a complex relationship, and the health implications of a poor relationship for all concerned. Here are the examples identified in the present literature review (e.g., Berdes et al., 2007; Brown-Wilson, 2008; Clare, Rowlands, Bruce, Surr & Downs, 2008; Clark et al., 1990; Chan & Pang, 2007; Chou et al., 2001; Clarkson, Hughes & Challis, 2005; Chappell, Havens, Hollander, Miller & McWilliam, 2004; Cohen, 1998; Connolly & O'Reilly, 2009; Davies & Nolan, 2004; Gamiel & Hazan, 2006; Häggström, Mamhidir, & Kihlgren, 2010; Kayser-Jones, 2003; Kellet, 1999; Kellet, 2007; Lee, Woo & Mackenzie, 2002; Leutz, 2010; Maddox, 2003; McCloskey et al., 2007; Rantz, et al., 2002; Rodrigues, 2010; Sterns & Kahana, 2007; and Tucket, 2005). Additionally, there have been literature reviews and discussion papers regarding older people's long-term care policy and practice, (Bourbonnais & Ducharme, 2010; La Rue & Watson, 1998; Melcher, 1988; Reiss, and Tishler, 2008(a); Reiss et al., 2008(b); Rodrigues, 2010; and Shadish, 1989), although the majority of this research focuses on care provision outside the UK, and predominantly within the United States of America (USA). Within these examples various epistemological, theoretical and methodological perspectives have been utilised, with some reflecting those adopted within this PhD thesis.

For example, one qualitative study explored the identity construction of residents from a symbolic interactionist perspective to explore how stigma was experienced between older people living in sheltered accommodation compared to those living in a care home in Israel (Gamliel et al., 2006). Residents were

found to construct the sheltered accommodation positively and as place of recreation associated with youth, consumerism and fitness, whereas staff and residents perceived the care home 'as a place for 'old people' facing imminent death' (Gamiel, 2006, p360). Residents in sheltered accommodation constructed self-identity through denial of old-age and built symbolic bridges between their past experiences and their current involvement in collective life. In contrast residents living in the care home bought into a culture of labelling of other residents, and was seen in the collective and personal adoption of these single, consistent and enduring labels in the construction of an alternative 'self' or 'identity'. This collective discourse (labelling) effectively stripped residents of any sense of individuality and disregard their former roles, status and personality. Gamiel (2006, p.362) suggests 'the lack of privacy, hope for the future and role variation created an existential void in which any form of perceived individuality, whether positive or negative, was likely to be considered a form of deviance'. It has been suggested that in long-term institutions for older people personal labelling and gossip serves as positive means of identity construction, and of confirming social norms (Percival, 2000). Gossip may also provide protection in the discrepancy between social ageism and integration by providing an outlet that helps individuals negotiate an ageing identity and connect with the social world.

Other researchers (e.g., Clark, 1990; Sterns et al., 2007), have applied Goffmans' theory of the total institution (Goffman, 1961) in long-term care facilities for older people. The present thesis also draws on Goffman's seminal work conducted in mental institutions, that describes the 'total institution' as being an environment where residents are all from the same cohort (i.e., elderly), live in the same communal setting, engage with each other in the same activities, adhere to the same institutional rules, and have a limited degree of autonomy. As



barriers to the outside world are central concepts of the 'total institution' research explored whether failure to meet expectations of contact with the outside world had a negative impact on residents' psychological wellbeing (Sterns, 2007). Stern also applied Merton's theory of anticipatory socialisation to investigate whether there were any differences between residents that enter nursing homes on a voluntary or involuntary basis in how they 'anticipate the values, norms and behaviours that will be encountered in a new social setting' (Sterns, 2007, p.5). Stern's findings from interviews with residents suggest that factors that precipitated the move into long-term care had the greatest negative influence on perceived quality of life and satisfaction with care. Self-rated health and morale scores found that anticipatory socialisation had a significant negative impact on quality-of-life outcomes indicating that residents who were reluctant to move into the long-term care may be at greater risk of poorer health, morale, and functioning. Stern's study provided little support for the 'total institution' within participating nursing homes, which may be due to the fact that resident involvement in decision making and willingness to enter nursing homes was higher than usual. Suggestions to increase anticipatory socialisation that enhance the adjustment process included involving older people in the decision process, encouraging a pre-admission visit to address any concerns in advance of the move, and the orientation of prospective residents and their families to what to expect (Stern, 2007).

Further, Diane Heliker, (2007), explored qualitatively how the transition to long-term care homes can lead to loneliness, and a loss of identity and sense of meaning for older people. Heliker's research established the importance of connecting with others through story sharing where staff learned to share their own stories and actively listen to resident's and other staff's stories, which gave

new meaning to caring and being cared for. Story sharing has been found to facilitate the expression of meaning (Heliker, 2007), increase rapport between residents and staff (Kirkpatrick & Brown, 2004; Mayers, 1995), and provide a sense of healing for residents as well as giving them a voice (Picard, 1991). Thus, the use of storytelling or 'narrative' is justified in research conducted in long-term nursing homes for older people, and as such has been utilised in the present Health Psychology thesis.

Another study (McCloskey et al., 2007), utilised Foucauldian analysis (Foucault, 1982; and Foucault, 1997) to explore the experiences of nursing home residents in emergency care departments. They found that residents were stigmatised as being problematic due to their demand on resources and because their chronic needs were not always amenable to acute service provision. This view was informed by quantitative methods, which failed to consider context and resulted in subjectification of residents who became objects of inquiry. McCloskey, (2007) concluded that the social construction of nursing home residents by hospital Emergency Units are rooted in social, political, historical factors; that residents have been constructed as objects of knowledge and depicted as problematic and unworthy of health care. This resonates with Tronto's Ethic of Care that suggests ageism negatively impacts on the quality of care given. McCloskey suggested knowledge that informs practice that excludes contextual variables may not present a complete picture. This supports that a Critical Realist perspective and approaches such as Foucauldian analysis that take into consideration context, may successfully be used for the interpretation of qualitative data collected in the nursing home environment: as is the case in the present doctoral research.

However, existing literature suggests reductionist quantitative methods have been used in older people's nursing home research (e.g., Cohen-Mansfield et al., 2009; and Haslam, et al., 2010), which are unable to elicit the lived experiences of participants and arguably 'reinforces capitalist power thereby disempowering the more vulnerable within our society' (Crossley, 2010 pp. 1-14). Despite the fact some quantitative measures have been especially adapted for use with people experiencing dementia or older people living in nursing homes (e.g., Kane, Bershadsky, Kane & Degenholtz., 2004) there remains a heavy reliance on measures that require literacy skills, which means that the voices of older residents living in nursing homes, and particularly those with dementia go unheard within research (McIver, 2005 pp. 180-199). Historically, psychologists conducting research have focused on individual determinants of behaviour measured using a variety of questionnaires e.g., personality and coping style, and a plethora of models such as social cognition models (e.g., Conner & Norman, 2008 provide a concise summary of such models). However, such methods are inappropriate for the exploration of lived experiences and for developing our understanding of what care means to older residents and staff in the nursing home environment, and the barriers to the delivery of such care: instead, the qualitative approach adopted in the present thesis is more conducive.

There are a few examples of qualitative studies that have explored resident and staff's nursing home experiences from a psychology perspective (e.g., Antaki, 2007; Harmer, 2008; Heliker, 2007; and Hubbard et al., 2003). These conclude that it is possible to include older people with dementia in research (e.g., Hubbard, 2003), and that there is limited understanding and training among nursing home staff regarding activities that are meaningful to vulnerable older residents experiencing dementia (Harmer, 2008). Harmer found resident

activities were impeded by staff shortages, and the psychological benefits of such activities were often under-acknowledged by staff and relatives in favour of the physical care needs of residents. This emphasis on physical needs is supported the present author's qualitative research exploring barriers to the delivery of a quality dining service in nursing homes (Dunn, 2014). This study from a Health Psychology perspective found that mealtimes were dominated by the medical model of care that was manifested through routine working practices and staff's 'labelling' of residents by their medical condition, and where the quality of interactions during mealtimes was impaired by staff shortages (Dunn 2014). Overall, there is very little nursing home-related literature specifically within the present authors' discipline of Health Psychology (e.g., Heponiemi et al., 2006; and Flick, et. al., 2010). With the exception of Flick (2007, 2009) most have adopted a reductionist perspective. Such individualistic reductionism that focuses on the medical model of care does not consider how health behaviours relate to the social, economic and cultural context, nor does it draw on the more person-centred social disability model that is deemed to be a more appropriate approach to caring for older people with dementia (e.g., Alzheimer's Society, 2003; Brooker, 2004; and Gallagher, Wainwright, Jones, & Lee, 2008). Thus, a more critical approach has been adopted in the present thesis to explore and inform understanding about 'care' in nursing homes in the UK.

## Summary of the Contextual Review

This contextual review outlines the development of models of care that claim to promote personhood and hence dignity conserving care for older people. It highlights barriers to adopting such models of care in the UK's culture of institutional care that is steeped in policy based on instrumental rationality and institutional allegiance to instrumental trust (Brown, 2008). Instrumental rationality involves the focus on clinical governance, risk aversion, and systemised and rationalised management. Such instrumental rationality was evident in present literature that tracked the development and implementation of legislative and regulatory interventions in response to concerns about poor care. Economic constraints, rationalised (task focused and for-profit) models of care, and a failure to involve service users when developing care services, have had a negative impact on the quality of Health and Social Care service provision for older people in the UK.

This review demonstrates that high staff turnover, staff shortages, staff occupational stress/burnout, ageist attitudes and behaviour by staff towards older people, and inadequate or inappropriate staff training impair the relationship between Health Professionals and older care recipients. The emphasis on developing care and gaining the trust of care recipients through cognitive and tangible means ignores the emotion work involved in communicative trust. This is important because communicative trust that evolves in the interaction between care-givers and care recipients is integral to all of the relationship/person-centred care and dignity conserving care models presented. Findings highlights the need to address such issues because a positive Health Professional/care-recipient relationship is considered pivotal to good quality care. Finally, the review

suggests a lack of research using qualitative or mixed methods approaches, and research specifically addressing the psychosocial dynamics of the carer-resident relationship in nursing homes.

## **Chapter 2: Ontology, Epistemology and Methodology**

The introduction provided an outline of the focus of this doctoral research, the specific aims and research questions explored, and the overall methods used to achieve this. The contextual review (chapter 1) drew on existing literature and outlined the history of nursing home care for older people in the UK from its growth in the 1990's to present day. Having specified the aims, questions and context of the research, the present chapter outlines the rationale for the first-person writing style adopted by the author, and also the ontological and epistemological lens and methodology used to explore the research questions.

### **Writing Style Adopted**

When writing a PhD thesis, the writing style generally advocated is to position the researcher in the third person as this is considered to be more academically and scientifically objective (e.g., Brewer, 2007). However, within qualitative research some discourage writing in the passive voice, particularly in the method section where the researcher should make explicit what actually happened during the research (Silverman, 2004; 2005). Social psychologist Michael Billig (2011) also recommends populating scientific writing with the author in order to make explicit the actions of the researcher, and to attend to how the personal characteristics of the researcher may influence the outcomes of the research. Due to the critical and therefore reflexive nature of this thesis, I have therefore chosen to write in the first person as it represents my experience, actions, and the consequence of my actions when seeking to understand the life worlds of the participants in my research. Similarly, I also make explicit the individual actions (speech or otherwise) of participants in my research by providing a pseudonym, for reasons of confidentiality. As the research was conducted within institutional settings where formal work roles exist, for reasons

of clarity, it was sometimes necessary for me to refer to participants in their position as a group member rather than as an individual participant, for example nursing home Manager, Registered Nurse (RN), Care Assistant, Activities Coordinator, visitor, or resident. However, I have avoided this where possible in order to minimise my objectification of research participants.

## Ontology, Epistemology and Methodology

In this chapter I first outline the ontological and epistemological Critical Realist positioning of this thesis and provide examples of its applications within Critical Psychology. Second, I present my methodology including the rationale for Thematic Analysis of thesis study data. This analysis is conducted in accordance with Vivienne Braun and Victoria Clarke's (2006) conventions of Thematic Analysis from a critical stance, and was influenced by Critical Thematic Analysis (Lawless & Chen, 2019). Finally, I outline the structure of this thesis including a brief summary of the content of each chapter.

## Reflections

To maintain a critical approach to qualitative research, Chamberlain (2000) suggests that it is important for researchers to avoid methodolatry, a term used to describe researchers being overly concerned and prescriptive about research methods without first attending to, or even failing to address issues of ontology and epistemology (epistemophobia). This practice is common within research, although more so in quantitative research. That said, critical psychology texts on conducting qualitative research (e.g., Burr, 2005; Crotty, 2009; Silverman, 2004), also place methods chronologically prior to ontological and epistemological considerations in their guidance on the steps to carrying out research. On reflection, when I began my PhD as a 'rooky' researcher I was naive to issues of



methodolatry and epistemophobia. I blindly followed the guidance of on 'how to do qualitative research in psychology' texts believing the contents were strict rules to adhere to, rather than a range of interchangeable research tools to be selected, bespoke to each research question. My misdirection was exacerbated by the fact that in the first year of my doctoral studies I was unclear of my specific ontological position, knowing only that my personal views were neither radically positivist nor radically relativist. However, I was conscious that my values and beliefs were more in keeping with a critical perspective. As my thesis was exploratory and therefore data-driven, it was necessary for me to begin collecting my data prior to theorising. I temporarily cast aside my uncertainty about ontology and epistemology and, using bracketing techniques, I was able to identify the dominant discourses in the first ethnographic observation study data. These discourses lent themselves to a critical approach, which in turn enabled me to consolidate the ontological and epistemological underpinnings of my research early in the research process. This allowed me to check that the methods that I had sought ethical approval for during the early stages of research process continued to be compatible with the Critical Realist position of the research. However, whilst immersed in the staff focus group study data, I became hypnotized by the trappings of methodolatry, coerced by the safety of attending to issues of rigor and validity. Consequently, my analysis became merely descriptive and was devoid of reflexive interpretation grounded in theory. Once illuminated to this discrepancy by my supervisory team, I was able to once again critically re-engage with the data. My rationale for adopting the Critical Realist position within this doctoral research is outlined in the remainder of this chapter.

## Ontology

Ontologically speaking realists suggest the world exists independently of our representations of it (Searle, 1995). In contrast, relativists reject this stance and consider the world to be socially constructed, for example, through language (e.g., Edwards, Ashmore, & Potter, 1995). However, neither acknowledge the position of the other, resulting in an ontological stalemate that serves to inhibit unity within psychology research. By means of consolidation, Critical Realism acknowledges the contribution of both human agency (realism) and social influences (relativism) in the construction of 'reality' (Bhaskar, 1975a). Critical Realism acknowledges a real world independent of our knowledge of it, open and closed systems, causal mechanisms, and wider social influences in the construction of 'reality'. It also recognises human agency, thereby bridging the ontological gap between empiricism and postmodernism (Archer, Bhaskar, Collier, Lawson & Norrie, 1998). Rather than the positivist idea of empirical predictability, and the purely interpretive and existential construction of reality depicted by some relativists, Bhaskar (1975) emphasised deeper level mechanisms as central to the generation of empirical phenomena. Where positivists see causality as being universal and predictable, Critical Realism suggests that causality generates tendencies rather than fixed outcomes, exists on many structural levels, and is both emergent and context driven (Bhaskar & Lawson, 1998). This represents an ontological change in emphasis from events or the 'observable' to mechanisms in regard to causality. Further, and contrary to extreme relativism, Critical Realism acknowledges both social constructions and human agency as objective and 'real' in nature, rather than subject only to the interpretations of researchers. Therefore the 'real' is central to Critical Realism, and something is real if it has a causal effect. Bhaskar's ontological position of

'real' and how reality is generated via structures and mechanisms is explained in the following section: Epistemology.

### Epistemology

Bhaskar (1975a) suggested reality consists of not only material realities but also artefactual, ideational, and social realities referred to as structures, that themselves comprise of levels such as rules, relations, powers, resources and practices (Archer et al, 1998). Any given 'reality' is the result of a unique blend of these 'structures'. In keeping with this idea of what is 'real', the present research considers that nursing home 'care' is already constructed when older residents enter into it due to an interaction between these structures. For example, structures influencing nursing home care may comprise of the breakdown of the nuclear family (social structure), an increasing older population with physical impairments and/or cognitive impairments (material structure), the idea that older people are dependent, lack capacity, and need to be cared for (ideational structure), and the consequential provision of institutions in which older people are 'cared' for (artefactual structure). Bhaskar also proposes that integration between structures in such a way enables objects connected to these structures (e.g., rules, relations, practices) to exert power. This is achieved through mechanisms that subsequently produce effects that are outcomes of these structures (Archer, 1998).

Within Critical Realism generative mechanisms are causal in nature and are 'real'; yet it is not always possible to observe or measure mechanisms empirically as they lay dormant until triggered, and may be untraceable or counteracted by the action of other mechanisms (Alvesson & Skollberg, 2000). The dormant nature or effects of active mechanisms is referred as a tendency. For example,

in the context of nursing home care, if an older lady living in the community is suddenly incapacitated following a fall it could trigger 'mechanisms' driven by the structural level of 'family values', and may cause the daughter to leave employment to care for her older mother at home. However, this 'mechanism' may be counteracted and rendered untraceable by 'mechanisms' within the structural level of 'economic constraints' that drive the daughter to return to work to financially support other dependents. The consequence of this may be that her older mother has to be admitted into a nursing home. Therefore, Critical Realism provides an explanation for infinite outcomes depending on interplay between given realities, their structures, and the levels within structures. These interact to activate mechanisms, the most dominant of which produces an effect (tendency).

Further, Critical Realism offers an alternative to the extremes of relativist and realist perspectives by theorising that mechanisms work at social, material, archaeological and ideological levels to elicit effects. Effects are generated by structures that precede and determine action and provide a basis for understanding such action (Alvesson et al., 2000). Within Critical Realism human agency is defined where the individuals are seen as 'objects' that actively engage with pre-determined realities rather than through subjective individual interpretations of reality. For example, within the present research power would be considered to exist where objects (e.g., residents or staff) connect to structures (e.g., the nursing home social structure) through a series of causal mechanisms, rules, resources, powers, relations and practices within the structure: resulting in effects on realities. Over time these effects may change both the structures themselves (e.g., working practices) and the individuals or groups that exist within those structures (e.g., the beliefs and behaviour of residents and care workers). Therefore, Critical Realism provides a structured yet

flexible theory of how participants construct reality within the extra-discursive (non-discursive) constraints they currently inhabit, such as material and social structures. As such, this positions discourse within context through the extra-discursive (Sims-Schouten, Riley & Willig, 2007).

Hypothetically, in the context of the present research, when examining the action orientation of residents talk in relation to nursing home care, extra-discursive features may include embodied constructions of old age as a chronic illness, incapacity and reduced independence. This may be the result of mechanisms activated via socio-economic and political structures that render care in the community inaccessible. This in turn may determine the material organisation of the nursing home as an acceptable space for the delivery of 'care' for older people that are perceived as lacking the capacity to live independently at home. Within Critical Realism it is suggested that these extra discursive features are contextual. Therefore, when applying this theory to the present research contextual features may inform care workers and residents accounts of nursing home care. The Critical Realist approach therefore facilitates the exploration of material practices and informs understandings of the relationship between our social and physical environments. Consequently, Critical Realism provides an ideal philosophical lens through which to examine the present doctoral research questions, which necessitate the exploration of both wider contextual influences on the delivery of nursing home 'care' (constraints that exist in the material world, and in the power of institutions), and embodied accounts of what 'care' means to individual care givers and care recipients (e.g., beliefs, values, feelings and emotions).

## Criticisms of Critical Realism

Critical Realism has been generally criticised by realists for attributing causality to something that is not visible to us, and for making claims to concepts that it is argued are unsupported and unrealistic, such as the idea that a mechanism is triggered whenever individuals interact with structures (Alvesson, 2000). In contrast, from a relativist perspective it is suggested that Critical Realism is too inflexible, lacks reflexivity, and that the extra-discursive is in fact a discursive accomplishment and is therefore always reducible to discursive practices (e.g., Edwards et. al., 1995). As Critical Realist language is derived from natural science and physics, relativists suggest it is inappropriate for use within social science, has no systematic differentiation between discursive and extra-discursive, and that data interpretation is a reflection of the researcher's own political standpoint rather than that of the subject (Potter Edwards & Ashmore, 1999). In contrast, Critical Psychologists suggest that in addition to material possibilities and personal-social histories, social constructionism tends to ignore the body or discuss it metaphorically or only as text, rather than acknowledge that subjectivity exists in the form of embodied interaction (Nightingale & Cromby, 1999). Because Critical Realism acknowledges that individuals interact with structures and trigger mechanisms, and that wider structures are embodied by individuals, it allows psychologists to explore more deeply how such structures are embodied beyond the realms of language, for example through feelings and emotions (Cromby, 2007), and beliefs (Cromby, 2012). As Critical Realism philosophically acknowledges both realist and relativist positions, Critical Realists have drawn on numerous theoretical perspectives to inform our understanding of materiality, embodiment and political structures, and have documented diverse extra-discursive constraints on our constructions of the real. Due to word limit

constraints these cannot be addressed in detail here, although excellent commentaries are available (e.g., Nightingale et al., 1999; and Parker, 1992; 1999; 2007).

Thus, the Critical Realist epistemological perspective is considered most relevant for the present doctoral research for two reasons: First, realist criticisms are negated by focusing on the three factors of embodiment, institutions and materiality; and second, relativist criticisms are addressed through the use of extra-discursive features that provide a flexible means for individuals to structure accounts that explain their actions (Sims-Scrouten et. al., 2007). This also provides a useful analytical tool to determine why one account is used over another. The 'Methodology' adopted in the present doctoral research is aligned with the Critical Realist perspective and is described in the following section of this chapter under three headings: 'Data Collection Methods'; 'Procedure'; and 'Analysis'.

## Methodology

### Data Collection Methods

I conducted appropriate training to equip me to carry out data collection, analysis and write up of the present doctoral research (see appendix 0.6). The data collection methods I used were adopted in order to gain insight into nursing home care from a Critical Realist perspective (see 'Summary of Procedure' below). First, I conducted ethnographic observations at organisation (meso) level in participating nursing homes using visual methods (photography) (Study 1; Chapter 3). This approach has been found to give insight into physical environments and the use of space and place in nursing homes for older people (e.g., Craig, 2017). At individual (micro) level I chose data collection methods

that enabled participants to speak freely about the topic of interest. This includes a focus group with four nursing home staff using photo-elicitation and object elicitation (Study 2: Chapter 4), and one-to-one interviews with fourteen nursing home residents using photo-elicitation (Study 3; Chapter 5). A full description of the methods used is detailed in each study chapter.

## Procedure

First, to inform my understanding of how nursing home care is constructed I collected data at various structural levels focusing on institutions, materiality, and embodiment. In order to critically explore institutional and material use of place and space at the meso (organisation) level, I conducted ethnographic observations in three participating nursing homes (Chapter 3). I then conducted a contextual literature review (Chapter 1) to determine potential macro level extra-discursive influences on the material use of place and space, and care policy and practice at the meso-level (i.e., within participating nursing homes). To further inform my understanding of potential extra-discursive influences at the meso-level I also carried out participatory diagramming and graphic elicitation interviews exploring nursing home managers' perceptions of care. Combining these methods has been found to be successful in promoting researchers' understanding about the broader relationships and power structures that influence an organisation, including in a clinical setting (Crilly, Blackwell, & Clarkson, 2006; and Umoquit et. al., 2008). However, the joint decision was made by me and my supervisory team to omit the manager interview study data set due to the large volume of rich data already collected. Instead, this study will be written up separately as part of a methodology paper to demonstrate the effective use of participatory diagramming and graphic elicitation methods specifically within the nursing home context.



In addition to identifying the potential extra-discursive influences on nursing home care at organisation level, I also explored nursing home staff and resident participants' embodied meanings of 'care'. This included their accounts of the psychosocial dynamics that exist in the carer/resident relationship; and the challenges they face in maintaining the carer/resident relationship. In order to do this, I gathered qualitative data during an object/photo-elicitation focus group study with four nursing home staff (Study 2, Chapter 4), and photo-elicitation one-to-one interviews with fourteen nursing home residents (Study 3, Chapter 5). To avoid methodolatry I used orthographic transcription for staff focus group data (Study 2: Chapter 4) and resident interview data (Study 3: Chapter 5) because it lends itself to many forms of analysis, including Thematic Analysis (Howitt, 2010a; 2010b). Participants' accounts of care were explored with reference to how they positioned themselves in relation to the extra-discursive influences found in each of the three participating nursing homes at the meso-level (Study 1, Chapter 3), and those previously identified in existing literature (Contextual Review, Chapter 1). These findings are critically discussed in Chapter 6 along with proposals for further research and potential applications of the present study findings in practice. A detailed account of ethical considerations and how participants were recruited is provided for each study within the body of each study chapter.

The methods used for data collection and data analysis for each of the three studies included in this thesis is summarised below in 'Diagram 1: Overall Methodology'.

# Overall Methodology

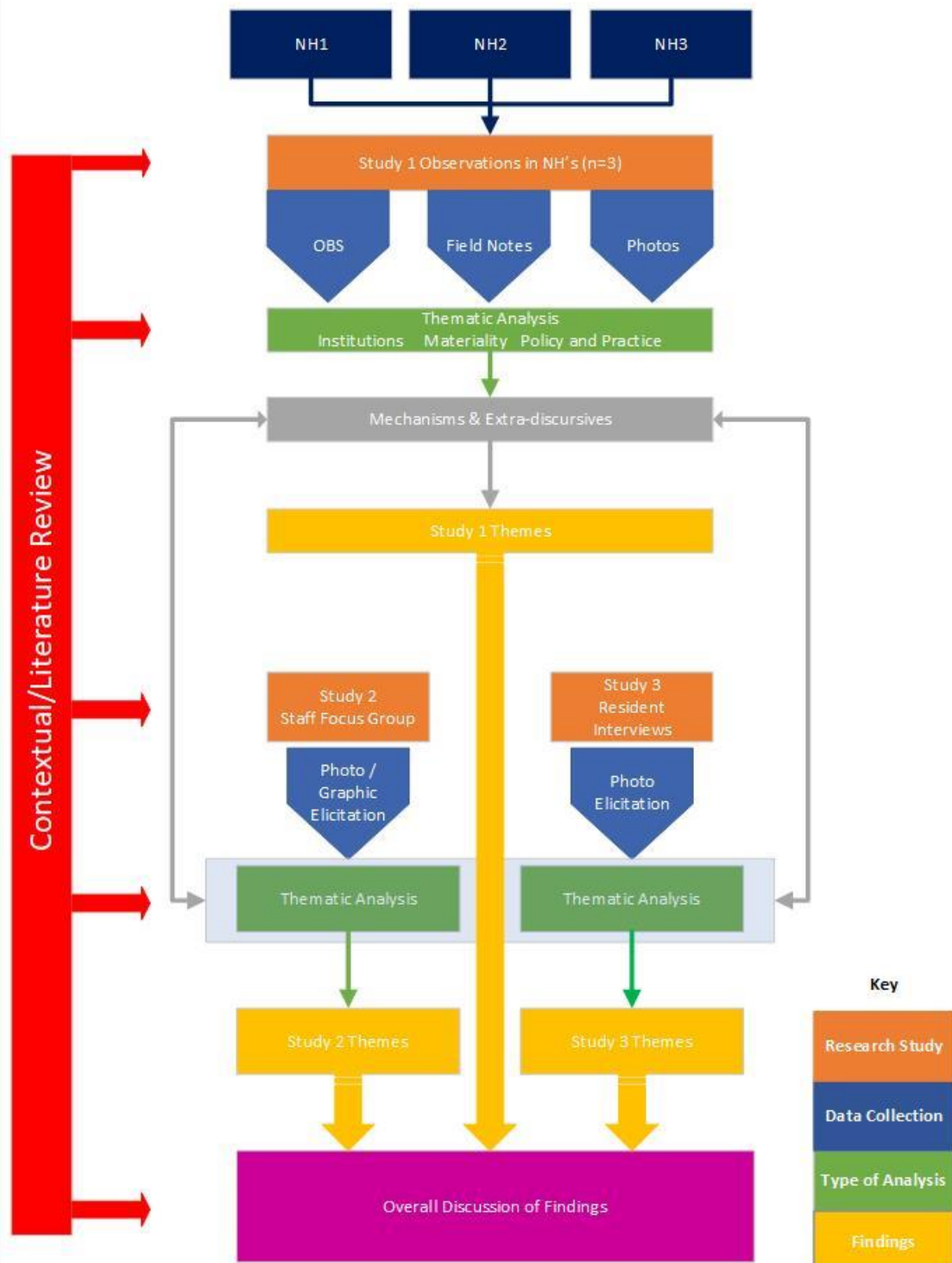


Diagram 1: Overall Methodology

## Analysis

### *Thematic Analysis*

Within this research the relativist and realist positions of the diverse research questions are bridged using the Critical Realist lens. This critical approach is used to analyse and interpret each data-set both individually and collectively in relation to the research aims and questions. The present thesis is explorative in nature, data driven rather than theory led, and seeks to examine the underlying structures and ideologies that shape the content of the data. Therefore, the method of analysis chosen is an inductive (data-led) and latent (interpretative) Thematic Analysis (Braun et al., 2006) influenced by the critical approach of Brandi Lawless and Yea-Wen Chen (2019). This critical approach to Thematic Analysis was conducted on each of the three qualitative data sets included in the thesis (i.e., Chapter 3, Study 1; Chapter 4 Study 2; and Chapter 5, Study 3).

Once the critical positioning, and the data-led and interpretative nature of the analysis was decided upon, the six phases of Thematic Analysis (Braun, 2006) were followed for each of the three individual data-sets included in the thesis. Phase 1 'Familiarising Yourself With Your Data' included: looking through researcher field notes (ethnographic observation study) and photographs (all three studies); watching audio and video recordings and reading orthographically transcribing the data (from the staff focus group and resident interviews studies) multiple times; and making notes of initial ideas as they arose. Phase 2 'Generating Initial Codes' required systematically attending to features of interest in the data, coding them, and then collating them into initial groups. For example, I did this by annotating transcribed data by code, adding each code reference and associated extracts onto an excel spreadsheet, and then numbering and colour coding them to distinguish between initial groups. Initial coding identified

repetition, recurrence, and/or forcefulness of any given discourse within the data, and patterns of meaning or salience to participants either individually or collectively: for example, the conflict between the personal and professional care ideologies that all participating staff expressed during the focus group.

Phase 3 'Searching for Themes' involved sorting the initial groups of coded data into themes and ensuring all data relating to that theme was included. At this stage, repeated, recurring or forceful patterns found in Phase 2 were explored in relation to wider societal ideologies: For example, how participants' individual and group perceptions of care work as important yet undervalued are interlinked with wider societal care-related ideologies. Phase 4 'Reviewing Themes' required that each theme was checked to be relevant to the coded extracts (Level 1), and also the data-set (Level 2) in order to provide themes that reflect the analysis, and more importantly the data. Phase 5 'Defining and Naming Themes' entailed fine-tuning each theme to reflect the story that the data unfolds by clearly defining and naming each theme. Finally, Phase 6 'Producing the Report' involved selecting the most appropriate extracts and data examples to reflect the story of each theme, and writing the analysis and thesis in relation to the research questions and existing knowledge.

### *Study-Specific Thematic Analysis*

I first conducted a Thematic Analysis of data from the literature review (Chapter 1: Contextual Review), combined with the data set collected during an 'Ethnographic Observation Study' (see Study 1; Chapter 3). This combined data set was analysed drawing on Michel Foucault's critical theory that infers knowledge equates to power, and his methodology 'Genealogy and Archaeology' as interpreted by Jean Carabine (see Carabine, 2008): the analysis and findings

is presented in Chapter 3 (Study 1 - Ethnographic Observation study). During analysis of the 'Ethnographic Observation Study' data set the institutional, material and embodied structures that were most prevalent within the data, and also within the literature review data, were identified as extra-discursive factors (see Chapter 3).

Thematic Analysis was then conducted on each of the two data-sets collected at the micro-level within participating nursing homes via a staff focus group (Study 2, Chapter 4), and one-to-one interviews with fourteen older residents (Study 3, Chapter 5). Thematic Analysis was used to determine how extra-discursive features found to be available contextually (see Study 1, Ethnographic Observations) are manifest in participants' embodied accounts (i.e., data from Study 2: Staff Focus Group, and Study 3: Resident Interviews).

When analysing data from the focus group with nursing home staff I conducted an inductive Thematic Analysis during initial coding of data during phase 1 and 2 in accordance with Braun (2006) to avoid imposing existing theory on the data. In phase 3 'Searching for themes'; phase 4 'Reviewing themes'; and phase 5 'Defining and naming themes' I coded data aligned with a more top-down and deductive approach. Phase 3-5 also involved identifying when participants attended to extra-discursive features identified in existing literature and the ethnographic observation data in participating nursing homes. I then systematically coded staff focus group data into overall themes that revealed how participants referred to extra-discursive features in their accounts of care, and their role as care-giver. Once arranged into themes I used the video recording of the focus group and also referred to the positioning of existing psychological theory (e.g., Hall, 2013; and Tajfel & Turner, 1979) to inform understanding of the

subject positions of participants (see Chapter 4 Study 2). The video recording of the focus group provided the finer details of participants' talk required for such analysis, for instance, intonation.

Finally, I conducted Thematic Analysis on resident photo-elicitation interview data collected in Study 3 (see Chapter 5) using the same conventions outlined above for analysis of staff focus group data (i.e., Braun, 2006; and influenced by Lawless, 2019). Analysis of resident interview data was influenced by Michael Murray (1997; 2000; 2004) and Christine Stephen's (2011) critical perspective that draws on Willem Diose's (1986) four levels of narrative. This has been found to provide insight into contextual, relational, and embodied accounts of reality within Critical Health Psychology (e.g., Murray, 1997; 2000; 2004; and Stephens, 2011) and within gerontology research (e.g., Phoenix, Smith & Sparkes, 2010). It has also been successful in photo-elicitation studies exploring patients' experiences in hospital (Radley, 2009; Radley & Taylor 2003a; 2003b) and homelessness (Radley, Hodgetts, & Cullen, 2005).

As author I argue that by selecting appropriate data analysis methods (i.e., Thematic Analysis, orthographic transcription, and triangulation of data), and by only including staff and resident's (micro-level) references to extra-discursive factors found in existing literature (macro-level) and in observations within participating nursing homes (meso-level), I have effectively established the 'real' from the perspective of participants in this doctoral research. This avoids the criticism that Critical Realism mirrors the researcher's rather than the participants' perspective (Sims-Schouten, 2007).

In conclusion, in this chapter I have outlined the ontological Critical Realist positioning of my doctoral research, which acknowledges the contribution of both

human agency and wider social influences in the construction of 'reality'. Here, individuals are seen as 'objects' that actively engage with pre-determined realities rather than through subjective individual interpretations of reality. I have explained how epistemology speaking mechanisms work at social, material, archaeological and ideological levels to elicit effects generated by structures that precede and determine action, and provide a context for understanding such action. I describe how Critical Realism has been criticised for attributing causality to the invisible, for being unrealistic regarding the causal nature of mechanisms, and for lacking rigor in differentiating between discursive and non-discursive. However, I suggest that these critiques are dispelled in the present thesis by conducting a Thematic Analysis of the data corpus that draws on existing psychological theories and critical approaches to the interpretation of qualitative data. A summary of the research method, procedure and approach to data analysis for each of the three studies included in this thesis was also presented.

### Ethics Approval

I applied for and obtained ethical approval for all three studies conducted in participating nursing homes from Sheffield Hallam University (appendix 0.1 and 0.2) and the Local Authority (appendix 0.3) ethics committees in accordance with the British Psychological Society (BPS, 2009) ethical code of conduct. I also obtained full Disclosure Barring Service (DBS) (formerly Criminal Records Bureau - CRB) clearance for research with vulnerable adults (appendix 0.4). Appendix 0.1 describes the procedure for and includes original versions of documentation used for recruitment of nursing homes, and nursing home staff and residents including: recruitment posters and letters; volunteer reply slips;

information sheets for participants; consent forms; and debriefing forms for each of the planned studies.



## **Chapter 3: Study 1 - Ethnographic Observations**

### **Introduction**

Chapter 2 outlined the ontology, epistemology and methodology adopted within the overall doctoral research. This chapter begins with the rationale for, a description of, and findings in the first of three studies included in the PhD thesis i.e., ethnographic observations in each of the three participating nursing homes. As outlined in Chapter 1, literature relating to theories and models of care suggests that context and the social and relational aspects of care are considered to be more appropriate in the delivery of long-term institutional care for older people. However, to the best of my knowledge there has been no research exploring historical/contextual influences on older peoples' nursing home care, how these discourses are embodied at organisational (meso) level, and how they are translated into care in practice. The present observation study in participating nursing homes aimed to fill this gap in knowledge. This chapter first describes the specific method of data collection (observation field notes and photographs) and data analysis (Thematic Analysis) used (see Diagram 2). It concludes with three themes found to be representative of the dominant macro level (national) and meso level (organisational) influences (extra-discursive) on nursing home care. These 'extra-discursive' informed subsequent analysis of micro level (individual) data gathered in study 2 (Staff Focus Group) and study 3 (Resident Interviews): the findings of all three studies were triangulated and discussed subsequently in the overall thesis discussion (Chapter 6).

# Observation Study Methodology

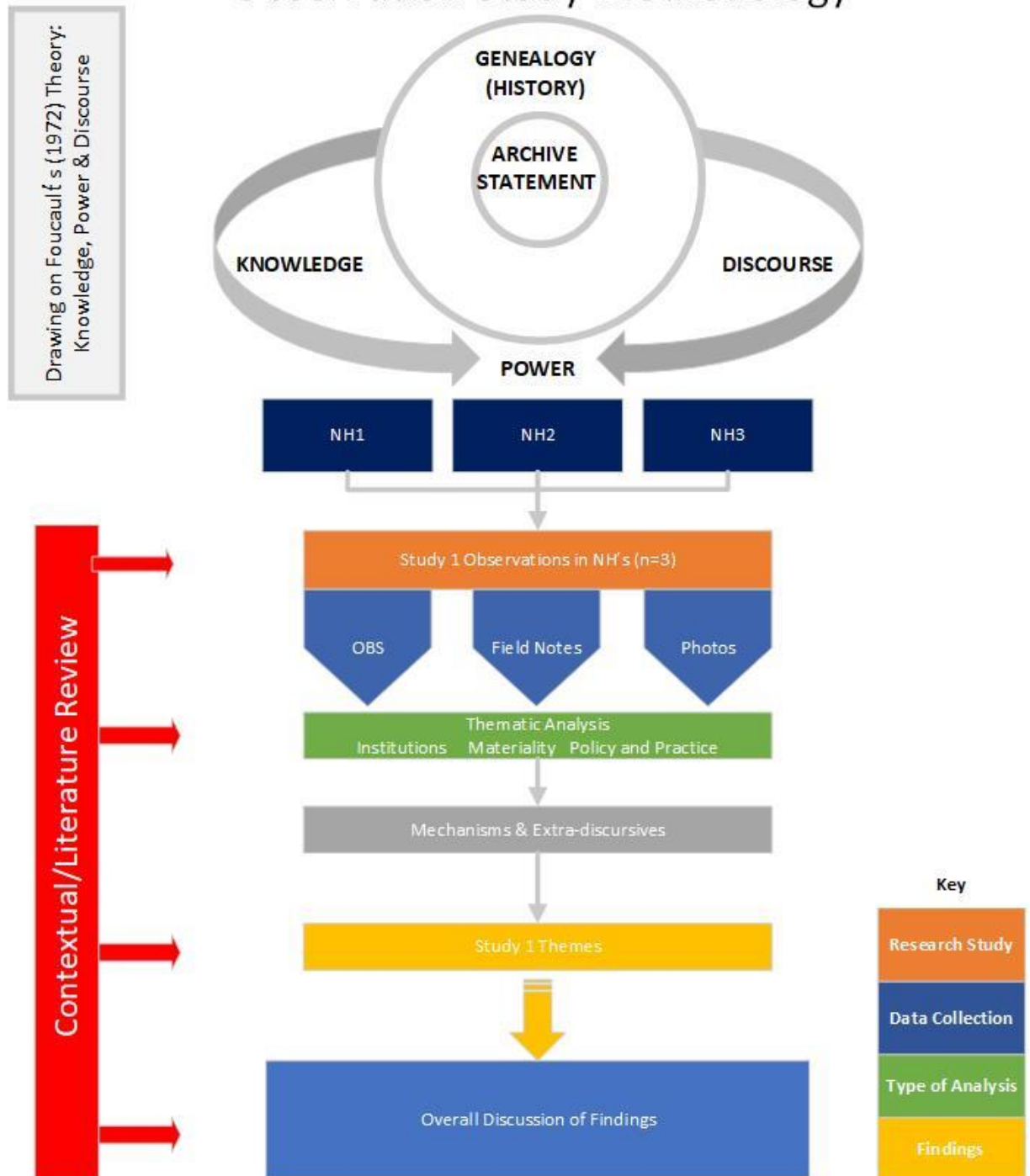


Diagram 2: Observation Study - Thematic Analysis drawing on Foucauldian Discourse Analysis (FDA) Methodology – Stage 1 and Stage 2

## Method

### Ethical Considerations

Sheffield Hallam University and Local Authority ethics approvals were obtained for the overall PhD research (see appendix 0.1 to 0.4). Present observation study-specific ethics documentation includes research information for participants (1.1), consent forms for observations (1.2) and photographs (1.3), and debrief sheet (1.4). A summary of how I negotiated the ethical issues specifically associated with ethnographic observations using photographs is also appended (1.5).

### Participants

To recruit nursing homes to this study I firstly sent out a mail-shot and reply slip (Appendix 0.5) to all 52 older people's private sector nursing homes in one Local Authority in the North of England. To minimise extraneous variables, I selected three similar nursing homes from eight that volunteered. All three nursing homes selected were purpose built in the last twenty-five years, had a comparable physical layout, and were of a similar size (30-40 nursing and care staff and capacity for up to 65 older residents). They also had the same owner, management structure, pay and conditions, philosophy of care, policies and procedures. I made follow-up phone calls and sent emails to arrange face-to-face meetings with the three selected volunteer nursing home managers in order to gain fully informed consent. Gaining access to nursing homes in order to gather ethnographic qualitative data can be difficult, and is exacerbated by research (such as undercover research by the media) that has placed institutional care in an unfavourable light. Therefore, in accordance with recommendations from previous ethnographic research in nursing homes (e.g., Kayser-Jones, 2003), I

developed and maintained positive relationships with providers and care recipients throughout the present study. I achieved this through reciprocity, objectivity, empathy, and appropriate ethical research activity.

### Data Collection – Reliability and Validity

Observation field notes and photographs were collected from the three participating nursing homes over the period of a month in May, 2011. Throughout the data collection/analysis process I adopted bracketing methods and reflexivity (see an account of my reflexive approach in appendix 1.6). This increased the reliability and validity of the research as it enabled me to portray a more realistic representation of the phenomenon. It also provided me with a buffer against the emotive aspects of nursing home care that had the potential to lead to personal emotional distress.

### Ethnographic Observations and Field Notes

Ethnographic observations are supported in research with cognitively or physically impaired older adults as traditional positivist quantitative methodologies, such as questionnaires, constrain their participation (McIver, 2005). Additionally, ethnographic observations have successfully contextualised understanding and interpretation of patients' experiences in health care settings (e.g., Radley, 1994; and Radley & Taylor, 2003a, 2003b), and have facilitated understanding of the complexity of the subject (Howitt, 2010b; and O'Reilly, 2005; 2007a; 2007b). As the present study aimed to inform understanding of the experience of those living and working in a health care context, I considered ethnographic data collection to be reliable, valid and methodologically justified.

I conducted observations on week days and weekends including various locations in each participating nursing home. Areas I observed included the

reception area, dining rooms, sitting rooms, bathrooms, laundry, kitchen, gardens/grounds, staff rooms, corridors, stairwells, lift areas, and Registered Nurses'/Care Assistants' work stations. In one of the three nursing homes there was also a small room equipped for hairdressing. I conducted observations in the twelve hours between 8.00hrs and 20:00hrs as this captured most of the activities and interactions of the day as this was the duration of a 'day' shift for most staff. I conducted one observation in each nursing home up to 21:00hrs to witness the transition from day to night care for both residents and staff. Each mini observation lasted between fifteen to thirty minutes per location. Dictaphone audio notes supplemented written field notes that I recorded in a notebook at the end of each observation. This also included documentation of my on-going theoretical interpretations in margins.

In line with Howitt's (2010b) recommendations, during observations I noted the environment, atmosphere, perspectives, people, interactions, events, and their development (see an example of my annotated field notes from one observation in nursing home 1: appendix 1.7). As this was my first 'field' observation in an active research project it was important for me to concentrate on developing recommended observational skills (Howitt, 2010b; O'Reilly, 2007b). My observation skills included watching, memorising, noting, recording in detail, describing, assessing, and analysing observed data. Additionally, I used overt and covert observation approaches to provide varied perspectives of the experience of care home living. I observed covertly how nursing home residents, visitors and staff interacted with each other, what they did with objects and how they responded to them. This allowed me to observe nursing home social life unobtrusively thereby reducing researcher observer effects. During covert observations I positioned myself as inconspicuously as possible, memorised

observations, and only made field notes after completing observations in order to further reduce observer effects (Howitt, 2010), and maintain participant confidentiality (British Psychological Society [BPS], 2009; Data Protection Act, 1998).

On reflection, I found it easy to covertly observe residents and visitors as they generally ignored me, presumably because my lack of a uniform indicated that I was a visitor. However, it was more difficult to observe staff covertly because staff did not know me, and due to safeguarding of residents, staff would approach me to enquire whether they could help me, and who I was there to see? I quickly recognised that it was important to build a relationship with staff in the first instance in order to gain their trust and acceptance. Thereafter, I introduced myself to nursing home staff and explained the aims of my research and also answered any questions they had, which facilitated their acceptance of me. Once staff was familiar and comfortable with my presence in the nursing home it became possible for me to conduct more covert observations. The central position of the nurses' station (desk/work space) on each floor in each nursing home was a vantage point that enabled me to unobtrusively observe activity in communal areas. My observations were enhanced by the installation of CCTV cameras in communal areas in one of the three participating nursing homes, which I viewed on screens from nurses' stations and the manager's office when vacant. Inconspicuous seating areas within dining rooms and sitting rooms and some corridors afforded me the opportunity to covertly observe individual/group behaviour and interactions, and the use of space over time. Each nursing home manager agreed that my on-going covert observations need not be announced, which further increased the likelihood of me observing naturalistic behaviour.

## Visual Data (Photographs)

Photography is widely used in ethnographic observations to contextualise our understanding and interpretation of various phenomena (e.g., Mitchell, 2011; Pink, 2007) including those within health care settings (e.g., Bell, 2002; Craig, 2017; and Radley, 2003a, 2003b). Based on this rationale and considering the ethical issues previously outlined (see ethics section of this chapter) I digitally photographed communal locations in participating nursing homes that were representative of the physical environment, and formed part of the reflexive ethnographic process (Alvesson et al., 2000; Pink, 2007). During ethnographic observations I took photographs in unoccupied communal areas and unoccupied resident bedrooms (with the manager's permission) to maintain the privacy and confidentiality of nursing home inhabitants. On one occasion I photographed an organised group activity for residents (bingo) with the consent of participating residents, staff and volunteers. I then securely stored, labelled, and where required anonymised photographs as outlined in appendix 1.5.

## Literature Review

After completion of ethnographic observations in three nursing homes I carried out a review of existing literature relating to nursing home care in England: the method and findings of the literature review is presented in Chapter 1. I used this information to contextualise nursing home care during Thematic Analysis of the present study data. The literature (discourses) that I found to pertain specifically to present observation study findings is presented immediately after the three data-driven themes in the Analysis/Findings section of this chapter.

## Thematic Analysis

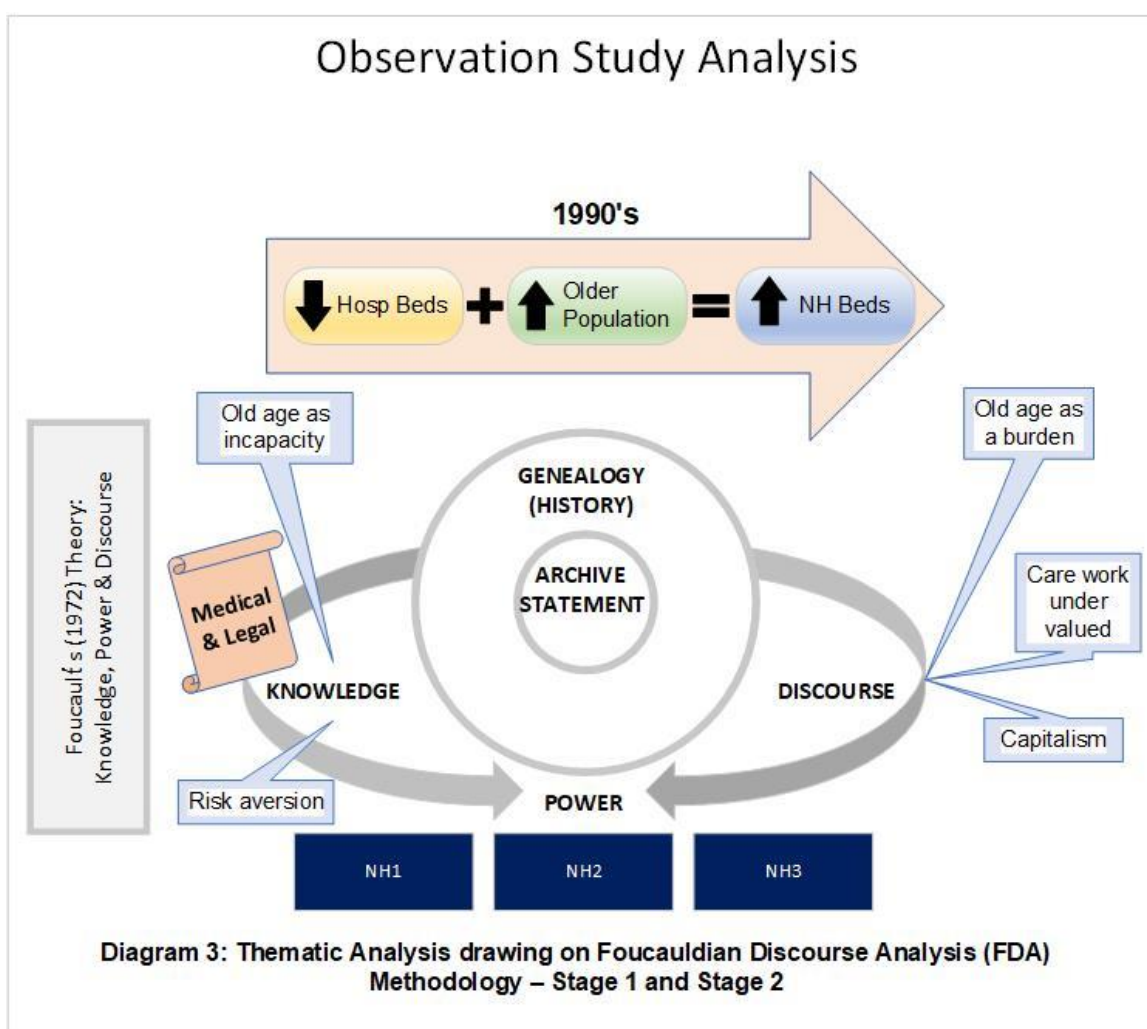
As outlined in Chapter 2 (Overall Methodology) I conducted an inductive, semantic and latent thematic analysis on ethnographic observation study data in accordance with Braun (2006) that was further influenced by Critical Thematic Analysis (Lawless, 2019). This included rigorous and systematic filtering for codes and subsequent themes within the data to the point of data saturation. During analysis I colour coded transcribed field notes by nursing home in order to distinguish the occurrence and prevalence of particular discourses both within and between nursing homes. I then annotated my field notes in the margins to identify discourse(s) within the data. I then sorted annotated data into sub-themes that were ultimately grouped into three main themes (see findings). An example of my annotated observation field notes can be found in appendix 1.7.

Photographs and existing documentation (e.g., nursing home policies and procedures) were grouped in a similar way to field notes, and similarities and differences within and between nursing homes were noted. I mapped hard copies and digitally uploaded photographs onto a floor plan of the nursing home which provided 'three-dimensional' visual data that gave me an insight and perspective into the use of space (Emmison, 2004). This process emphasised the similarities between the floor plans of each nursing home, and also the physical environment including landscaping, furnishings, décor, signage, equipment and storage. By noting the time of day and which day of the week the photograph was taken I was able to establish the use of space over time. Additionally, I arranged photographs into groups firstly within and then between nursing homes to identify dominant discourses. For example, photographs affording the opportunity for social interaction were grouped together in each nursing home. Areas observed included physical locations such as: sitting rooms; dining rooms; grounds and



gardens; conservatories; staff rooms; library; and notice boards displaying social signage (see appendix 1.10 for examples of photographs in each of the three participating nursing homes).

Present analysis drew on existing literature (outlined in Chapter 1) and Foucault's (1972) theory of knowledge as power, and his methodology 'genealogy and archaeology' (see appendix 1.8 for a full description). This enabled me to establish the dominant discourses within the data in relation to the construction and delivery of care at the meso-level (see diagram 3).



Applying Foucault's theory enabled me to identify and describe 'events' (contingencies) and discontinuities that form the truths (taken for granted), and structures of discipline and punishment in relation to nursing homes today. This included the identification of the action orientation of data to establish what is gained from using a particular discourse, as well as identification of the subject positions of people within a particular discourse. The implications of the object constructions and subject positions for opening up and shutting down action were then explored, as were the consequences for the subjective experience of the individual. My analysis notes that summarise the main findings uncovered during each of the six steps of analysis can be found in appendix 1.9. This approach permits consideration of external influences on the evolution of the 'object' (nursing home) including historical influences, which Foucault (1972) refers to as 'events' and 'discontinuity' (O'Farrell, 2005).

As the present ethnographic observation was conducted in an institutional nursing home environment, during my analysis of the data I drew on previous ethnographic research that explored health care institutions such as hospitals (Radley, 2003a;2003b), schools (Acker, 1999), and nursing homes (Treeweek, 2000). Additionally, I utilised research that explored institutional power: for example, the influence between guards and inmates in prisons (Goodman, 2008) and between staff and patients in hospital (Dingwall & Murray, 1983).




To summarise, the present study analysis draws upon Foucault's (1972) critical theory that infers knowledge equates to power, and his methodology 'Genealogy and Archaeology' that facilitated understanding of discourses within the institutional nursing home setting. Subsequent analysis of data collected in Chapter 4 (staff focus group) and Chapter 5 (interviews with residents) explored

how these macro/meso-level discourses are embodied at micro-level by nursing home staff and residents.

### Analysis: Presentation of Findings

The dominant discourses I found to be visible in nursing home care at the meso-level (organisation-level) are presented here in three main themes: First Medical Influences on the Environment, Staff and Working Practices; second Psychosocial Interaction and the Effect of Limited Resources; and third Legislation and Language as Power (see figure 5).

Firstly, I found that nursing home care is dominated at the meso-level by objectifying medical discourses that reflect wider discourses of old age as a time of disability and incapacity. Secondly, I found that the macro-level discourses of rationalisation and austerity were embodied at the meso-level, and were manifest in routine working practices, limited resources, and a 'for profit' business approach to care delivery. Thirdly, I found that risk-averse discourses at the macro-level were evident within care practice at the meso-level in the form of highly visible legislatively and regulatory driven signage and equipment; prohibitive rules and regulations; and staffs' use of language that was inconsistent with dignity conserving care. I also found that staff and residents self-regulated to the dominant discourses I found at both the macro-level and the meso-level. These findings are now presented in detail.

<b>Theme 1</b>	<b>Theme 2</b>	<b>Theme 3</b>
Medical Influences on Environment, Staff and Working Practices	Psychosocial Interaction and The Effect of Limited Resources	Legislation and Language as Power
		
1.1 Medical Environment	2.1 Psychosocial interaction	3.1 Legislation as power
1.2 Staff Hierarchy and Training	2.2 The Effect of Limited Resources	3.2 Language as power
1.3 Routine Working		

**Figure 5: Observation study themes and sub-themes**

#### Theme 1 – Medical Influences on Environment, Staff and Working Practices

Throughout the data medical discourses were evident in the physical environment of the nursing home (sub-theme ‘Medical Environment’), in the status and duties of nursing home staff (sub-theme ‘Hierarchy and Training’), and in the working practices adopted (sub-theme ‘Routine Working’).

### ***Sub-theme 1.1 - Medical Environment***

I found that institutions that deliver long-term care for older people who require care from a Registered Nurse are referred to as nursing homes. This generic term emphasised medical discourses in relation to institutional care for older people i.e., the term 'nursing'. Additionally, my observation study photograph and field note data showed that the nursing home physical environment and working practices also epitomised a medical approach to care provision. Examples of observation photographs in each nursing home (see figure 6) demonstrate how the physical environment including the floor plan, fixtures, fittings and contents of each nursing home were influenced by the medical model.



**Figure 6: Medical discourses in the nursing home physical environment**

For example, the photographic data in figure 6 showed that central to each building design was a nurse's station (desk space) (picture 1a) on every floor, with resident bedrooms containing medical beds (1b) running off corridors (1c) akin to those found in hospital wards. As in a hospital setting there were sluice rooms (1d), medicine dispensing trolleys (1e), and absorbent incontinence pads on chairs in some lounges (1f). There were three floors in two of the nursing homes and two floors in the third nursing home. CCTV cameras were present in communal areas in one of the nursing homes with three floors. CCTV facilitated observation of residents, staff and visitors by nursing home general managers (responsible for overall running of the nursing home), and nurse managers (in charge of residents' day to day care needs). This continuous surveillance of residents is typical of institutions such as hospitals and prisons, where patients/prisoners are monitored by those in a position of authority.

Medical discourses were also evident where sections of the nursing homes were distinguished by the physical/cognitive capacity of the residents living there. The area that accommodated more independent residents was referred to as the residential floor, the area with residents with physical impairments was referred to as the medical floor, and the area for residents with cognitive impairments such as dementia was referred to as the Elderly and Mentally Infirm (EMI) floor: the latter two floor names were derived from a clinical 'hospital' environment. In one nursing home each floor was allocated a colour to distinguish between the care needs of the older people residing there, green floor was the floor where residential residents lived, red floor was for physically impaired residents, and blue was the floor where cognitive impaired residents lived. Similarly, variations in the colour of soft furnishings were used to help staff, residents and visitors distinguish between nursing home floors as all of the walls were painted

magnolia, including residents' bedrooms. The only exception was the sitting room on the Elderly and Mentally Infirm (EMI) floor where a mural of an outdoor country scene was painted because residents with cognitive impairments were not allowed to go outside unescorted (see photograph 1). Door access to the nursing home was via coded door locks.



**Photograph 1 – Outdoor scene painted on the walls in sitting room on the Elderly and Mentally Infirm floor**

Most residents' bedrooms had en-suite toilets, and single rooms were approximately 10 square meters in area, which is smaller than the average prison cell and was consistent with other United Kingdom nursing homes (Dudman, 2007). Residents were not allowed to decorate their bedrooms but were able to bring personal items into their bedroom such as small items of furniture, pictures and trinkets, etc. Each resident's bedroom door was numbered and was

frequently used by staff on care-related paperwork, on notice boards visible around the nursing home, and verbally when referring to residents. This system of numerically identifying residents is similar to patient hospital numbers used in the National Health Service to identify and locate patients.

Although the nursing homes were generally clean and free from offensive odours, I detected aromas that are generally associated with clinical settings. For example, an antiseptic aroma was evident in recently cleaned areas and sluices (bodily waste disposal areas), and the smell of ammonia from stale urine was present on some sitting room chairs. The latter was usually in areas/chairs where residents with incontinence sat, and where staff placed absorbent incontinence pads on armchairs such as those seen in figure 6 (image 1f). These observation findings show that the nursing home environment is predominantly influenced by medical discourses.

### ***Sub-theme 1.2 - Staff Hierarchy and Training***

Akin to the physical environment, staff hierarchy and training within each nursing home was also found to be medically driven. The organisational hierarchy for staff delivering care was primarily based on medical knowledge where Care Assistants with National Vocational Qualifications (National Vocational Qualification level 1 & 2) in Social Care were subordinate to National Health Service medically trained Registered Nursing staff. Nurses employed in participating nursing homes included those qualified to provide general physical care to adults (Registered Nurses) and those who were qualified to support adults with cognitive impairments such as dementia (Registered Mental Nurses). Both Registered Nurse and Registered Mental Nurse training provides knowledge of anatomy, physiology, and dispensing of prescribed medication. Similarly,



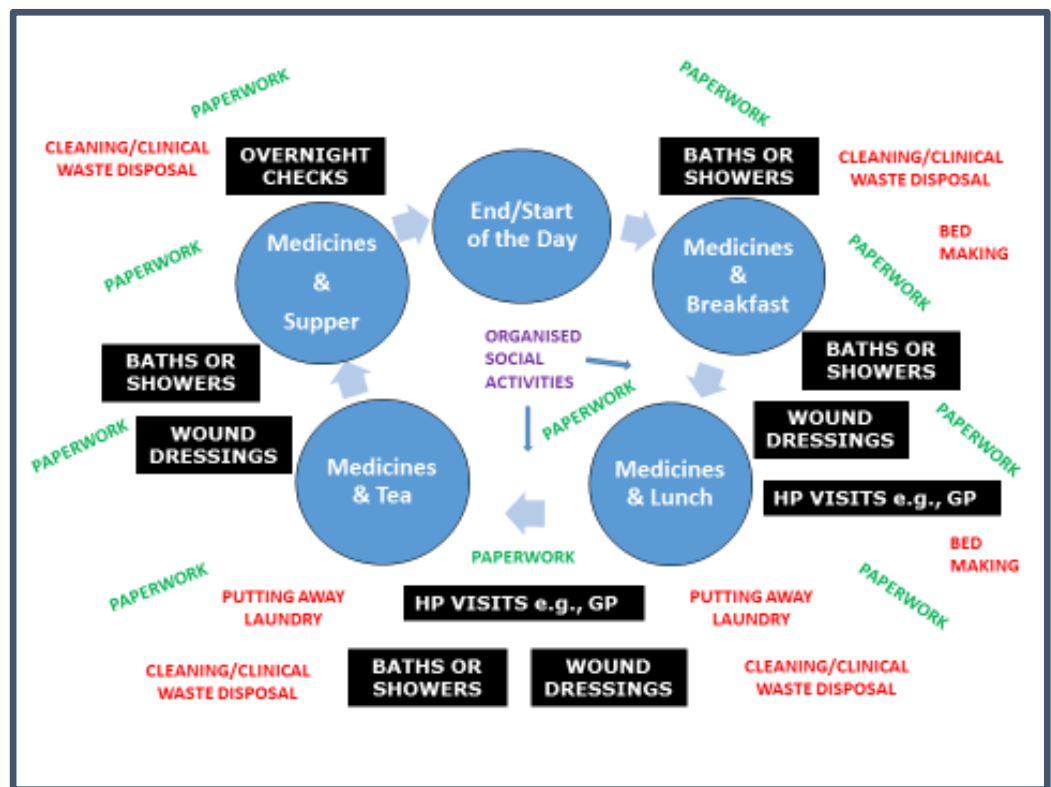
National Vocational Qualification courses for Care Assistants mainly included modules that provided knowledge on physical care provision, although some modules incorporated training on care of vulnerable adults such as safeguarding. In participating nursing homes all Care Assistants were either doing, had completed, or were about to start a National Vocational Qualification Level 1 (that is equivalent to one GCSE at grade D-G), or National Vocational Qualification Level 2 qualification (that is equivalent to one GCSE at A\*-C) in Health and Social Care.

The colour of nursing home staff uniforms formally depicted hierarchical status and job role and were medically determined as they replicated those used in National Health Service hospitals: namely maroon for the Nurse Manager, navy blue tabards/dresses for Registered Nurses; violet for Senior Care Assistants; light blue for Care Assistants; and white for ancillary staff. All staff wore badges stating their first name, surname and job title. A notice board in each reception area also displayed a picture and the name of each member of staff and their job title. The typical number of Registered Nurse and Care Assistants on duty for each shift was observed to be one Registered Nurse and 3-4 Care Assistants per floor in each nursing home. There were three floors in each nursing home, each with capacity for 22 residents: total nursing home capacity of 66 residents.

### ***Sub-theme 1.3 - Routine Working***

I also found routine working practices typical of National Health Service hospital care that centred on medically driven physical care interventions such as the dispensing of medication, and meeting residents' physical care needs. I have summarised the working practices I observed in a schematic (see figure 7) that

represents medically driven daily working practices adopted in each of the three participating nursing homes.



**Figure 7 – Schematic of daily routine working practices in nursing homes**

Following the arrows in a clockwise direction the schematic starts each morning with the physical task of assisting residents to get up, which is carried out by Care Assistants and includes helping residents with washing and dressing. Once up, residents had breakfast either in their own bedroom or in the dining room. The Registered Nurse dispensed prescribed medicines to residents during every mealtime from a portable lockable medicine trolley positioned close by (see figure 6, image 1e). This reinforced medical discourses of deficit during mealtimes, despite this being considered an ideal opportunity for social interaction (e.g., Dunn, 2014). Between dispensing medications Registered Nurses provided catheter care, changed wound dressings, accompanied General

Practitioners (GPs) during routine and call-out consultations with residents, and had responsibility for assessing, planning, implementing and evaluating residents' care plans. This list of duties and responsibilities is not exhaustive. RNs were observed as having very little time to interact with residents other than during such medically driven interventions. The interventions of RNs were found to determine when routine physical tasks were conducted by Care Assistants and ancillary staff.

Care Assistant work routines involved physical tasks such as assisting residents with their hygiene, dressing, dietary, toilet, and mobility needs. Each shift the Registered Mental Nurse/Registered Nurse or senior Care Assistant on each floor would allocate Care Assistants a number of residents to 'specifically' care for based on each resident's level of independence, and staff numbers. As there were around twenty-two residents per floor this was usually between five and seven residents per Care Assistant based on 3-4 Care Assistants per shift per floor. Due to limited physical resources (e.g., low staff numbers and only 1-2 bathrooms per floor) each resident was allocated a specific day(s) and time (either morning or afternoon) to receive a bath or a shower. Care Assistants were usually allocated two residents requiring a bath/shower per shift. Therefore, resident care was both medically and resource driven.

Other physical routines carried out by domestic staff such as cleaning schedules and laundering residents' clothes were dovetailed between inflexible medically driven routines. Similarly, formally organised social activities for residents (see Theme 2) were accommodated between physical care and mealtimes. Care Assistants, relatives or volunteers were observed escorting residents to/from organised 'social activity' sessions that were usually conducted

in a sitting room or dining area that would be converted into a temporary 'activity' space for residents. Care Assistants would then return to provide physical care to other residents or engage in non-interactive routine duties such as replenishing store cupboards, disposing of waste, making beds, taking items to/from the onsite laundry, and updating resident care-related written documentation.

In two of the three nursing homes permanent staff worked in the same area of the nursing home to provide consistency, increase familiarity and build rapport between staff, residents and visitors. Despite this, nurses and Care Assistants were observed working in different areas of the nursing home in order to accommodate staff shortages, even during the course of a single shift. In the third participating nursing home the recently appointed manager had introduced a permanent system of staff rotation between floors on a shift-by-shift basis. During my observations Administrators, nurses and Care Assistants spoke to me informally and said they found the introduction of new working practices by the new manager stressful. Further, staff in all three nursing homes said the unsocial/long working hours and physically and emotionally draining nature of the work often left them feeling too tired to socialise with family and friends outside work.

Summary Theme 1: This theme demonstrates how medical discourses determined the nursing home physical environment that was more representative of a hospital than a domestic dwelling. The duties and status of nursing home staff was based on medical knowledge where those with medical qualifications (Registered Nurses/Registered Mental Nurses) had greater status and power over those without i.e., other staff and residents. Routine working practices were task focused, medically determined, and prioritised residents' physical care

needs. Staff felt demotivated by rotating work placements, and reported being fatigued by the length of shifts and physical and emotive nature of the work. The introduction of change to institutional working practices also increased staffs' self-reported levels of stress.

## Theme 2 - Psychosocial Interaction and the Effect of Limited Resources

Despite the dominance of medical discourses and the emphasis on physical care in nursing homes, attention to psychosocial aspects of resident health and wellbeing were also observed and are presented in sub theme 1, 'Psychosocial Interaction'. In contrast, psychosocial interaction between staff and residents was impaired by routine working practices and economic discourses of austerity that are presented in sub theme 2, 'The Effect of Limited Resources'.

### ***Sub Theme 2.1 – Psychosocial Interaction***

#### *Organised Activities*

In each of the three nursing homes there was some formal attention paid to providing stimulation and opportunities for social interaction for residents. Each nursing home employed its own Activities Coordinator to organise social activities that were promoted via flyers on notice boards on each floor and in the reception area. Activities were available for a few hours each day Monday to Friday usually between breakfast and lunch (10:00-12:00), and between lunch and residents' evening meal (14:00-16:00). Activities observed included crafts, communal games such as bingo, coffee mornings, weekly visits by a hairdresser, and weekly religious services. Monthly activities included formal entertainment such as sing-along acts that incurred a fee to the nursing home. These were paid for with funds raised via events such as staff run fetes and raffles. Quarterly trips out via a hired minibus incurred a fee to residents and were limited to between 10-15 places due

to limited access to suitable transport and insufficient volunteers to escort residents. Each nursing home had the capacity to accommodate 66 people, however, the average number of residents observed attending daily activity sessions was an average of ten people. This equates to only a sixth of the residents living in the nursing home. I observed that residents attending formal activity sessions such as bingo (see photograph 2) were physically rather than cognitively impaired. This was partly because many of the organised activities were not suitable for residents with dementia or Alzheimer's, and due to insufficient staff on the Elderly and Mentally Infirm (EMI) floor to escort cognitively impaired residents to these sessions.

Access to activities was further limited where all social activities were cancelled for a week in one nursing home due to the Activities Coordinator being on annual leave. Therefore, resource constraints such as insufficient funding for activities and staff were observed to have a direct negative impact on the delivery of social activities and the opportunity for psychosocial interaction between residents, staff and visitors.



**Photograph 2 – Social activity session**

### *Visitors*

Visitors were observed to provide a valuable source of psychosocial support for residents. Although visiting times were unrestricted most visitors attended in the evening, and during the day at weekends, exceptions were usually either retired or unemployed. Visitors were fewer at times when residents received the majority of physical care i.e., early mornings, late evenings and mealtimes. In each nursing home I observed a few exceptions where visitors assisted with the hands-on care of residents. For example, providing support at mealtimes by sitting with the resident in order to assist and encourage them with their food. My observations found that most visitors provided psychosocial support to residents. This included engaging in active conversation such as conveying information and

reminiscence; shopping for personal items; and taking/escorting residents on trips outside the nursing home, such as meals out and residents' hospital outpatient appointments. Although visitors generally provided residents with a means of connecting with the outside world and offered important social support, they were sometimes observed as having a negative impact on the person they were visiting. This (usually) involved visitors who's relative had recently entered the nursing home. For instance, in one afternoon observation I conducted in a sitting room for residents, a daughter was visiting her recently admitted mother. The daughter became increasingly anxious at her inability to attract the attention of staff who were either on their breaks or engaged in routine tasks such as restocking linen cupboards and completing care-related paperwork. The daughter was disturbed by the agitated behaviour of other residents in the sitting room who were unattended by any staff throughout the forty-minute observation. The daughter's anxieties appeared to rub off on her mother who also became visibly agitated.

### *Key Worker*

In an attempt to meet the needs of residents and particularly those without regular/any visitors, a system was in place where residents were allocated a named member of the nursing and care staff as their 'key workers'. Their role was to ensure residents' physical and psychosocial care needs were met. For RNs this involved updating resident written care plans and medicine charts at least monthly. For Care Assistants the key worker role included reporting residents' shortage of clothing (see figure 8) and toiletries to a named representative of the resident (usually a family member or friend) to replenish items as required. The former issue of lost or damaged clothing while in the nursing home laundry system led to tensions in the relationship between staff and residents and their



visitors, mainly due to the financial cost to residents of replacing the item or sentimental value attached to certain items received as gifts.



**Figure 8: Lost or damaged laundry leads to tensions in care relationships**

Additional roles for Care Assistants as 'key workers' included recognition of significant dates such as resident's birthday and anniversaries and ensuring a card and celebratory tea with cake was provided by the nursing home. Both key Registered Nurses and key Care Assistants were required to engage, where possible, in psychosocial aspects of resident care such as conversation and reminiscence, and to be a point of contact for visiting friends and relatives. During my observations, nurses and Care Assistants engaged mainly in physical care and had little time to carry out their responsibilities in relation to residents' psychosocial needs. However, some staff provided psychosocial support when

off duty, for example, one carer provided resident manicures and supplied materials for this, and an off duty Registered Nurse and her family took a resident out for the day. Such gestures were acts of goodwill on the part of staff. Further, across all nursing homes most of the staff I observed on each shift engaged with residents in a positive way at least once while delivering routine physical care. This included staff using touch, gentle tones, humour, and encouragement to reassure residents when supporting them with their care needs.

### ***Sub Theme 2.2 – The Effect of Limited Resources***

#### ***Staff Shortages***

During my observations a Registered Nurse or Care Assistant was absent on each shift. During informal conversations I had during my observations nursing home managers each felt staff shortages increased staff workload, lowered staff morale, and led to sickness-related absenteeism. One nursing home manager voiced her concerns to me about general staff shortages at the organisation level and considered them to be the result of a shortfall in Local Authority funding for nursing home beds. She felt this led to cost savings on staff wages by nursing home owners in order to maintain profit margins. To put this into perspective the payment to participating nursing homes by the Local Authority for the fees of means-tested residents eligible for social care funding was capped at a maximum £397 per week. This equated to a shortfall of £40 per week per resident based on the mean average charged per room in participating nursing homes i.e., £338-£536 for a nursing care single or shared room. Nursing home staff salaries and wages were the greatest single cost, although remuneration of nursing home staff was less than National Health Service staff on an equivalent grade.

## *Communication*

When a member of staff was absent if a replacement worker (bank or agency staff) was unavailable, existing nurses and Care Assistants rallied round and supported each other to deliver residents' physical care needs. During observations I noted that the additional workload imposed by staff shortages and the tiring nature of care work adversely influenced care staffs' interactions with residents. This included staffs' closed body language, and minimal eye contact and verbal communication. This was particularly noticeable at the end of a working shift, especially where staff worked longer 12-hour shifts. I observed that staffs' communication with residents generally improved again in the period immediately following staff breaks, which took place approximately an hour before the end of a day shift. This suggests staff felt replenished after a short break.

Across all three participating nursing homes most residents were of White British origin. Further, nine out of ten nurses and Care Assistants observed were women, and one in four were migrant and/or of Black Asian and Minority Ethnic (BAME) origin. During interactions with staff whose first language was not English or who did not have the regional dialect/accents, residents were observed as having difficulty either hearing or understanding what staff had said: this included residents with and without a hearing impairment. On most occasions where this was observed, staff would respond by repeating themselves in a louder voice, which was usually ineffective. In a minority of cases staff slowed and clarified their speech so that residents could understand them, which was usually effective in relaying the required message.

### *Multi-functioning Space*

Although purpose built in the 1990s, each participating nursing home failed to accommodate the demands currently placed upon it such as storage, social activities and staff training. Space was observed to be a limited resource and communal spaces were observed to be multi-functional (for example see figure 9).

Space in the Nursing Home is used for multiple purposes. For example, here we see the dining room used for serving meals; dispensing medications and for conducting social activities.



**Figure 9: Space in the Nursing Home is used for multiple purposes**

I observed that resident sitting rooms and/or dining rooms were also used for delivering staff training, staff meetings, staff administrative activities, storage of equipment (e.g., hoists), weekly hairdressing sessions, organised activities (e.g., coffee mornings), and (if requested by those bereaved) for the wake following the funeral of deceased residents. Outdoor spaces including grounds and gardens were utilised for storage including clinical and general waste, items

of equipment for disposal, and car parking. Outdoor space was also used by residents, visitors and staff for social and leisure purposes such as sitting, smoking, and activities such as fund-raising fetes. The constant reshaping of space by staff to meet multiple requirements was observed to be time consuming, and therefore limited the opportunities for social interaction between residents and staff, while increasing staff workload.

Summary Theme 2: In this theme, organised social activities, visitors and the key worker system were found to provide psychosocial support to nursing home residents. However, economic constraints, medically driven routine working practices and insufficient space firstly limited the frequency, duration and quality of formally organised activities, and secondly reduced the opportunity for staff and visitors to engage informally with residents. Staff shortages, cultural differences (e.g., language barriers), lengthy shifts, and the physically and emotionally draining nature of the carer role were observed to impede staffs' ability to communicate effectively with residents. Such constraints at the macro/meso-level were found to impair the ability of nursing home staff and visitors to meet the psychosocial needs of residents.

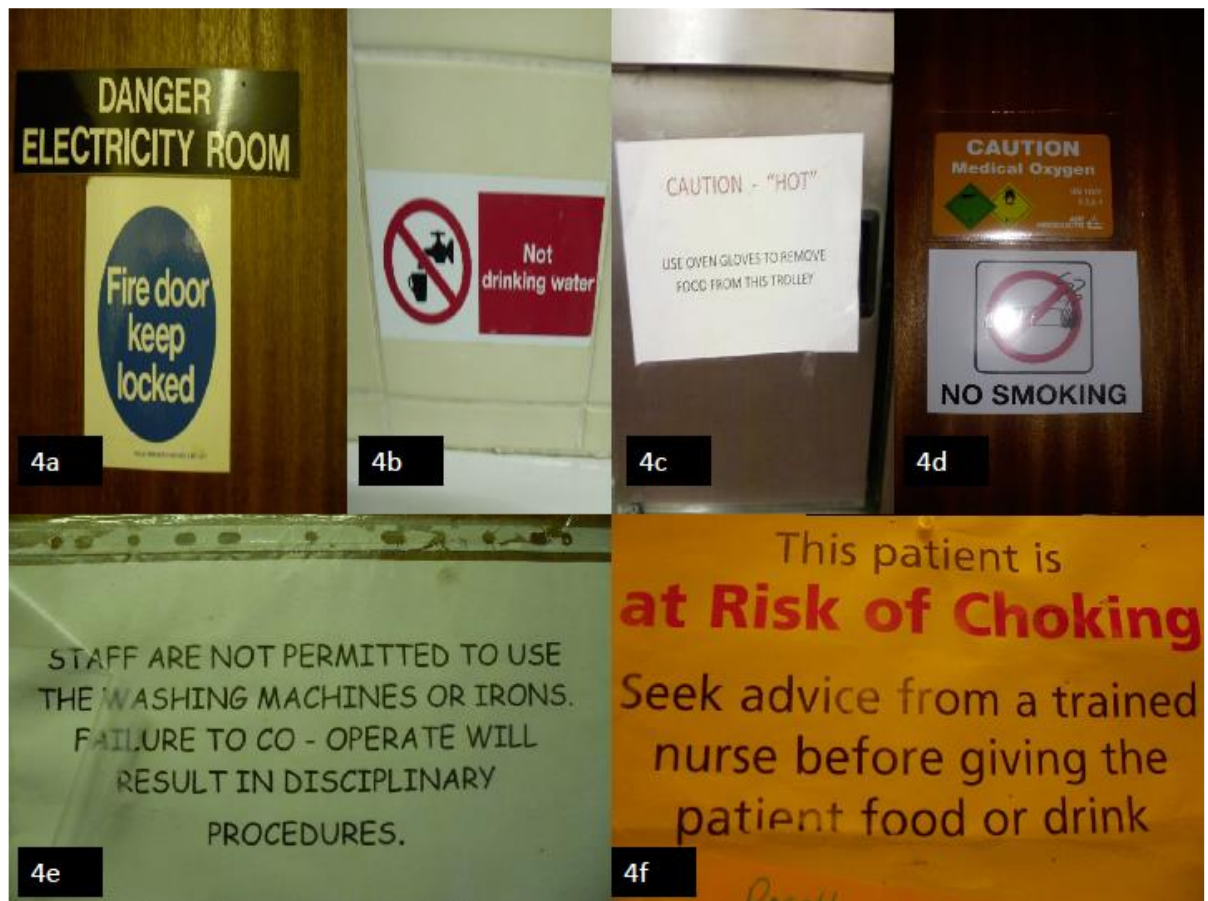
### Theme 3 - Legislation and Language as Power

#### ***Sub-theme 3.1 - Legislation as Power***

In response to wider discourses of concern about neglect and abuse of older people in institutional care the British Government increased its interventions to improve institutional health and social care provision in practice through regulatory bodies (e.g., Care Quality Commission, 2009; 2011b) and legislation (e.g., Mental Capacity Act, 2005; Mental Capacity Act, 2007; Health and Safety at Work Act, 1974). These risk-averse measures were intended to

safeguard older people living in nursing homes against institutional abuse, increase their rights, and provide them with greater choice in relation to care. Such regulatory and legislative discourses are visible at the meso-level both in the physical environment and working practices. For example, physical manifestations of the macro-level risk-averse discourses at the meso-level included security code locks on external doors. There was also restricted access to stairwells via doors that had two handles (one at the top and one at the usual height) that must be operated simultaneously to allow entry. In addition to preventing unauthorised access to the nursing home, these measures served to restrict residents' movements both within, and to/from the building. Additionally, restrictive health and safety related signage (e.g., prohibitive/warning notices see figure 10) and equipment (e.g., hoists, see figure 11) required under health and safety legislation was extremely visible in all areas, including residents' bedrooms.

In conversations I had with residents or witnessed during my observations, some residents expressed that the nursing home was a place with rules and regulations that they had to adhere to, and said that they would never consider it to be their home. For example, prohibitive discourses included signage warning about danger and/or restricting action (e.g., figure 10: image 4a-4f). Some domestic and care staff expressed feeling demoralised and restricted by rules that discouraged the use of individual initiative.

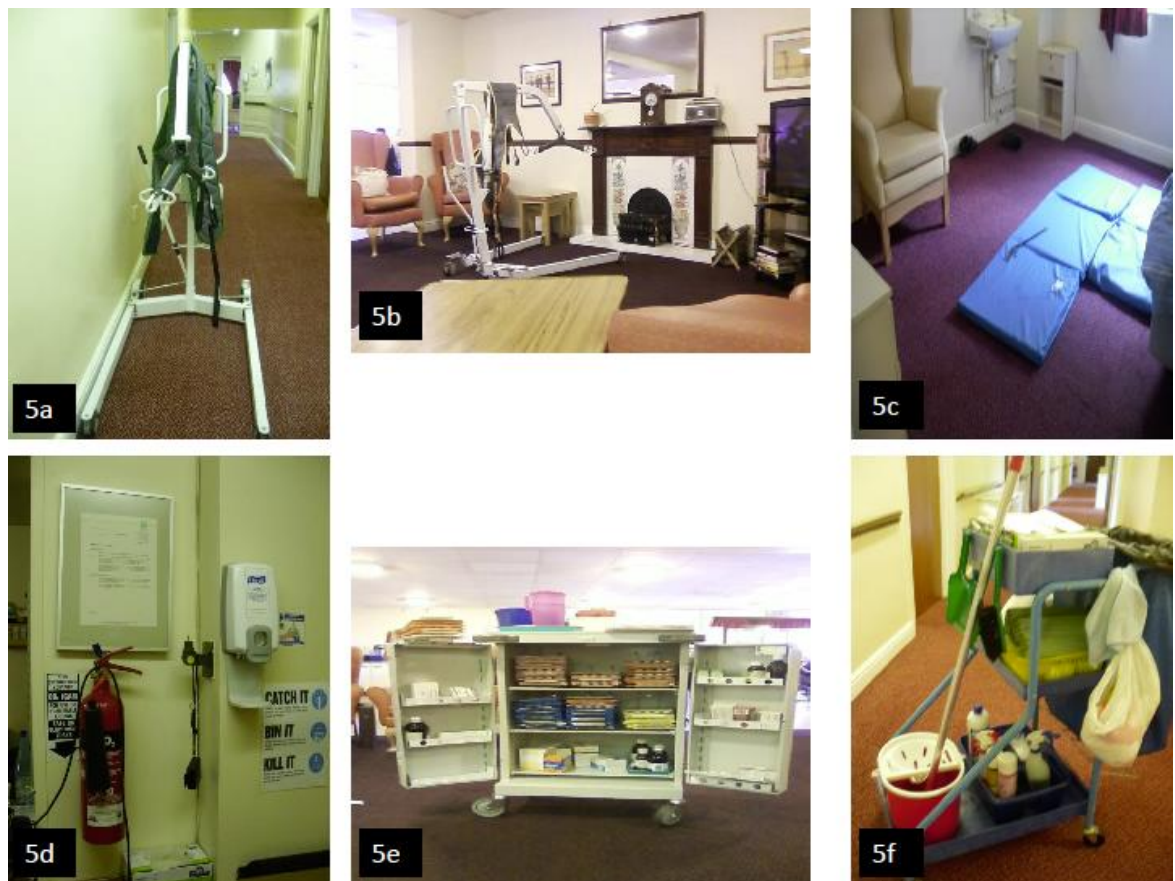


**Figure 10: Risk adverse discourses**

Further, Registered Nurses said that completing health and safety related paperwork impinged on time that could be spent delivering hands-on care to residents. During my observations one Registered Nurse took thirty minutes to fill out an accident form in triplicate and update a resident's care plan due to the resident accidentally grazing her hand on a chair in passing. Overall Registered Nurses were found to spend approximately two thirds of their shift on health and safety/safeguarding related and other care-related administrative tasks. I observed that Care Assistants spent approximately twenty minutes per resident per shift completing such paperwork. This was the equivalent of two hours paperwork for Care Assistants responsible for six residents, which is one sixth of a typical twelve-hour shift.



In addition, staff also said that there was not enough time to place moving and handling hoists in their designated storage space due to their frequent and obligatory usage under health and safety legislative requirements. Consequently, health and safety equipment were regularly left in communal public areas (see figure 11) such as corridors (image 5a) and sitting rooms (image 5b), and private areas such in residents' bedrooms (image 5c & 5d). Other equipment was also highly visible including nurse medicine trolleys (image 5e) and cleaning or laundry trolleys (image 5f).



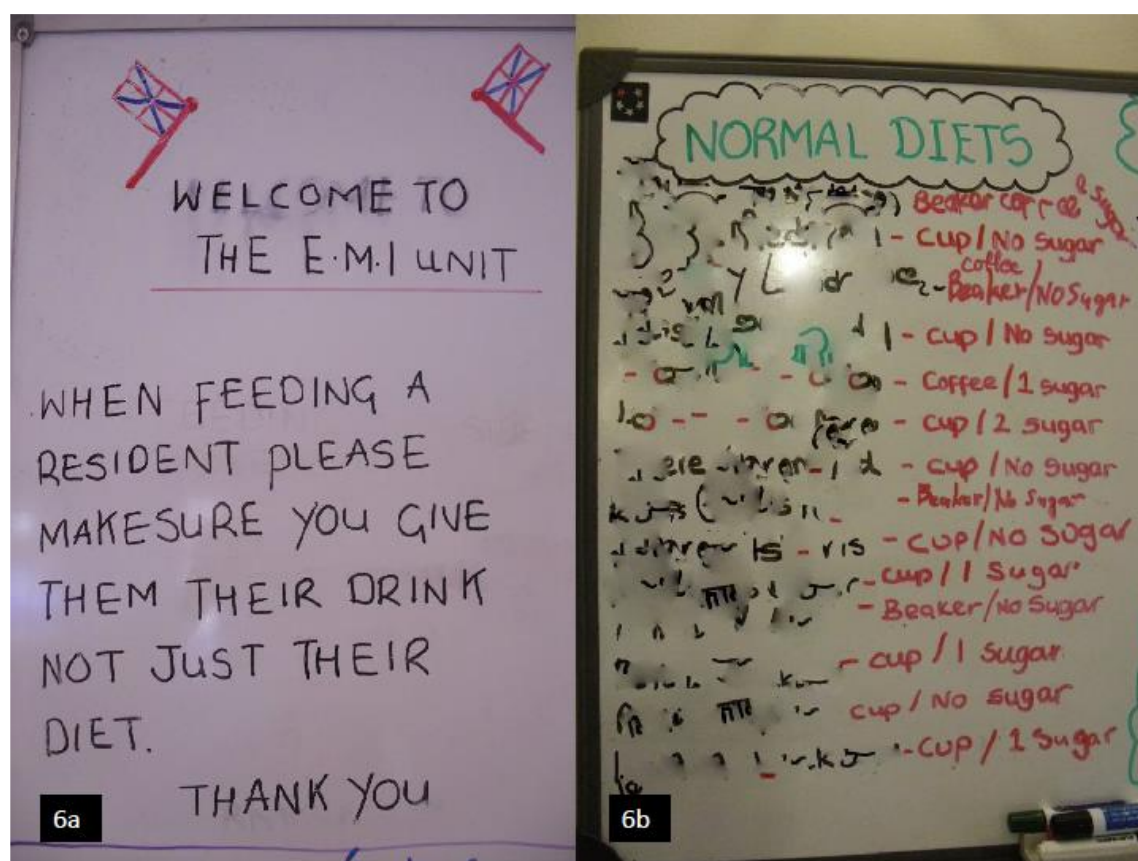
**Figure 11: Medical and health and safety related discourses**

### ***Sub-theme 3.2 - Language as Power***

The language found in written communications on notice boards in dining rooms in one nursing home (figure 12) used infantilising language, and language that



medically labelled residents. The first sign on the Elderly and Mentally Infirm (EMI) floor (figure 12 image 6a) demonstrates the use of infantilising language, a term that describes discourse that positions adults as children (Radley, 1994) and therefore subordinate. In figure 6a, staffs' language positions residents as children through the phrase 'when feeding a resident make sure you give them a drink and not just their diet'. The term 'feeding' is often used when referring to babies rather than in reference to adults, and depicts older residents as dependent recipients of care. This placed the carer in a 'parental' position of power over residents similar to the parent/child relationship.



**Figure 12: Discourses of infantilisation and medical labelling**

The second sign on a whiteboard in public view in a dining room on the medical floor in the same nursing home (figure 12 image 6b) listed the names of residents alongside their dietary needs, for instance, normal diet, diabetic diet or soft diet. These categories label residents based on medically determined dietary restrictions. For example, residents without physical impairments were labelled 'normal diets', residents with diabetes were labelled 'diabetic diets', and residents with swallowing difficulties were labelled 'choke risk'.

During my observations, Registered Nurses, Care Assistants and catering staff referred to residents using these medical labels when communicating with each other at mealtimes. In each nursing home Care Assistants were observed seating residents together on the basis of their dietary needs rather than according to residents' preferences. Consequently, residents that required assistance with their food and drink during mealtimes were usually seated together on one table rather than offered a choice. This made it easier for Care Assistants to observe and assist residents with their dietary requirements.

**Summary Theme 3:** The macro level legislative discourses that aim to reduce risk and increase resident autonomy and choice were found in all three participating nursing homes. This was evident in highly visible health and safety signage and equipment and bureaucratic time-consuming form-filling. Additionally, staff adopted language that both infantilised and labelled older nursing home residents.

Findings – Literature review: Establishing contextual influences on care

When applying Foucault's archaeology and genealogy to analysis of my aforementioned observation study data it was necessary to determine historically

the wider context in which nursing home care evolved. I achieved this by conducting the literature review (see Chapter 1) that informed my understanding of how macro-level discourses may have influenced the visible meso-level discourses that I found during my observations in participating nursing homes. The specific literature that demonstrates the macro-level historical/contextual events and discontinuities that correspond to the most dominant discourses within participating nursing homes, are presented below and are summarised visually in diagram 3. Most of the relevant literature I found fell mainly between 1980 and 2000 because older people's nursing homes in England increased in number significantly during this period (Kerrison & Pollock, 2001; Wood, 2001). I found discourses that have influenced nursing home care were from wider social, economic, cultural and political structures. These discourses were from a number of sources and included public, private and third sector organisations (e.g., policy and procedures and legislation); academia (e.g., research peer review journal articles, books, and literature reviews); professional bodies (e.g., research and practice); and the media (e.g., TV, radio, online and newspaper reporting).

#### *Demographic events*

One of the main reasons for the increase in the number of nursing homes in the 1990s was the result of a national increase in longevity over the last 30 years (National Statistics Online, 2011) and social mobility resulting in an increase in the number of older people requiring institutional health and social care.

#### *Political and economic events: rationalisation and legislation*

Within participating nursing homes, the environment, working policy and practices were dominated medical, legislative, risk averse and rationalised discourses. This was influenced by political and economic events in the 1980's

such as the government's capitalist economic policy to rationalise public services, resulted in the legalisation of the commissioning of public sector services to the private and voluntary sector (National Health Service and Community Care Act, 1990). This included Health and Social Care services and led to a shift in older peoples' care provision from the public sector (National Health Service) to the private sector, which had a 'for profit' business model (Kerrison, 2001; Wood, 2001). Psychologist Michele Crossley (2010) described how this represented postmodern rationalisation of health care and the introduction of consumerism whereby medical dominance was challenged (Hardey, 1998) and patients became customers and active purchasers of care rather than passive recipients (Bury, 1991; 1998). Within the literature I found this was legislatively supported through interventions such as the White Paper Working for Patients (Department of Health [DOH], 1989), and the Patient's Charter (Department of Health [DOH], 1991). In participating nursing homes, it was evident through a physical environment and working practices steeped in regulation.

Following Griffith's review of National Health Services management (Department of Health and Social Security [DHSS], 1983), a private sector approach to management was endorsed based on economic rationality that included auditing, cost-benefit measures, and performance indicators. Simultaneously the shift of older people's care into the private sector prompted discourses of concern that profit margins may compromise the quality (Schlesinger & Dorwart, 1984; Shadish, 1989) and consistency (Beckford, 2011; Royal College of Nursing [RCN], 2010) of care, and have a negative impact on older nursing home residents' health and mortality (Grant, 1985; Lieberman et al., 1983; Shultz, 1977). Despite such concerns, by 2001, there were 4,170 general nursing homes providing 144 thousand general nursing home beds, and 1,050

mental nursing homes providing 32 thousand mental nursing home beds in England (Community Care Bulletin, 2002). In 2010, this number increased to 4,608 nursing homes and 13,475 care homes without nursing facilities (CQC, 2011a) employing 355,000 care workers and senior care workers (Eborall & Griffiths, 2008).

### *Medical discourses*

Since the 1980's, National Health Service nurses whose training is primarily based on the medical model of care, were recruited to manage/work in the burgeoning private sector, a practice that continues today. This has perpetuated the medical model of care in nursing homes. The medical model of care originally evolved from the medical objectifying 'gaze' of patients by health professionals (Foucault, 1963). According to Crossley (2010:17) the hegemony of the biomedical model is representative of objectification: a reductionist process associated with modernism. Here, people (patients) become the passive 'object' of the powerful medical expert, marginalised by the medical knowledge and medical language of health professionals. The medical model dominated National Health Service long-term hospital geriatric wards for older people and institutions for the 'infirm' from the 1950's (Goffman, 1961) to the exclusion of contextual, social, and relational discourses that are central to personhood, and person-centred dignity conserving care (e.g., Brown, 2008; Kitwood, 1997; McCormack, 2004, McCormack & McCance, 2006; Nolan, 2001; Nolan et al., 2004, 2006; Ryan et. al., 2008).

### *Culture of ageism and care work as undervalued*

Discourses of old age as disability and infantilising of residents by staff was found in participating nursing homes. Exploration of literature suggests macro-level discourses that may have influenced this. Historically the National Health

Service rationalised/objectifying approach to care reflected the cultural, social and economic values of the time (Williams, et al., 1980) that treated chronically mentally ill individuals as an underclass who were undervalued and ignored (Levine, 1979), and old age as a time of deficit, dependence and incapacity (Tronto, 1993;1998). Such values prevail in twenty-first century Britain fuelled by ageism portrayed in the media and in health and social policies (Hatch, 2005; Kane et al., 2004; Kane & Kane, 2005). Age discrimination also permeates the provision of Health and Social Care services including wide spread physical abuse, neglect, and a lack of autonomy and choice for older people in receipt of homecare (Equality and Equal Rights Commission, 2011), hospital care (Royal College of Nursing [RCN], 2010; Royal College of Psychiatrists, 2013), and nursing home care (e.g., CQC, 2011a).

This observation study found that staff shortages and absenteeism were evident in participating nursing homes and a general under-resourcing of facilities to meet the diverse needs of nursing home residents and staff. In accordance with Joan Tronto's influential paper 'Ethic of Care' (Tronto, 1993) such cultural, social, and economic discourses reflect a historical undervaluing of older age by invalidating older peoples' care needs, and depicting care work as menial and womens' work. Such discourses were evident in an independent review of care workers that concluded social care work is poorly paid (an average of £14,000 per annum), and is mainly conducted by women (85%) and people from Black, Asian and Minority Ethnic (BAME) groups (29%) (The Cavendish Review, 2013). For care workers such undervaluing of their role was found to be demoralising and increases staff turnover (Coward et al, 1995; Gaugler et al., 2009; Harris-Kojetin et al., 2004). Indeed, the stress associated with the increasing psychosocial demands of patient care is reflected in National Health Service staff

absenteeism for sickness that was found to be highest (6.9%) for Care Assistants than other staff delivering care (NHS Information Centre, 2010). Given the increasing psychosocial demands of patient care, research indicates that health professionals are in need of more psychosocial training to reduce staff stress and absenteeism, and improve patient care (e.g., Maben et al., 2010). This topic is covered in the staff interview study (Chapter 4).

### *Regulation and risk aversion*

The present nursing home observation study found that the physical environment, and working/care policy and practice were imbued with discourses of prohibition and risk aversion. This has been influenced by spiralling reports of abuse and neglect of older people in private sector nursing homes (e.g., BBC News, April, 2014; and CQC, 2011a, 2011b, 2014a, 2014b, 2015, 2017a, 2017b, 2018a, 2018b, 2019) and National Health Service hospitals (e.g., Department of Health [DOH], 2013) leading to government political and legislative interventions to improve care service provision and the rights of older care recipients and care workers. Government interventions have included the introduction of the National Services Framework (NSF) for older people (Department of Health [DOH], 2001) emphasising person-centred National Health Service care that focuses on the individual care recipient; stricter regulation of health and social care provision through the introduction of the Care Quality Commission regulations (CQC, 2009) and Healthwatch (Health and Social Care Act, 2012); and legislation to promote the safety of nursing home workers/inhabitants (e.g. Health and Safety at Work Act, 1974) and resident autonomy (e.g., Mental Capacity Act, 2005; Mental Capacity Code of Practice, 2007; Equality Act, 2010). Michele Crossley (2010:28) notes that such policy, regulatory and legislative discourses are synonymous with the United Kingdom's postmodern capitalist society and aim to promote individual

agency, thereby opposing prohibitive modernist discourses of rationality. They represent a more procedural and reflexive model whereby individuals can contribute to knowledge and make decisions, and are judged by the standards of the community to which they belong. Therefore, rather than comply with existing order we construct order through a process of self-regulation to community norms (Hardey, 1998). However, such discourses are also indicative of subjectification that was found in the present observation study. Subjectification is an extension of the organisational 'gaze' in the form of reflexivity and self-regulation to wider discourse of control and discipline, which serves to restrict rather than promote agency (Bury, 1991;1998; Foucault, 1977). For example, I found macro-level medical and risk-adverse discourses restricted residents' personal choices (e.g., smoking).

In the overall discussion of findings (Chapter 6) I consider how these macro-level discourses of medical objectification, rationalisation and subjectification, and statements about older people and the nature of care work, are transformed in the archive and made visible in participating nursing homes.



## **Chapter 4: Study 2- Focus Group with Nursing Home Care-giving Staff**

### **Introduction**

Despite the development of theories, models and definitions of 'dignity' and 'care' (outlined in Chapter 1) there is still a lack of understanding about why abusive care practice prevails in nursing homes, and how nursing home staff and older residents perceive 'dignity' and 'care'. Therefore, in this chapter I first outline a dearth in existing research in the respect of staff and resident perspectives of dignity and care. Secondly, I present my focus group study that, using Thematic Analysis, explored what care meant from the perspective of care-giving staff in participating nursing homes.

### ***Current Literature exploring 'Dignity' and 'Care' from the perspective of care givers and older people receiving care***

#### ***Perceptions of 'dignity'***

Although there is no agreed definition of the concept of 'dignity' Jacobson's (2007) review of existing literature concluded that dignity comprises of two main concepts, human dignity and social dignity. Human dignity refers to the moral and rational capacity of humans to treat people with respect, and social dignity relates to both dignity-of-self (self-respect, self-confidence) and dignity-in-relation (impact of the reflected reactions of external others on the individual's sense of self-worth). Prior to 2010, despite concerns over the lack of dignity in institutional care very few studies attempted to determine what dignity means from the perspective of: older people (Gallagher, et al., 2008; Woolhead, Calnan, Dieppe, & Tadd, 2004); older patients (Jacelon & Henneman, 2004); hospital nurses and patients (Baille, 2009; Walsh & Kowanko, 2002); hospital nurses only

(Heijkenskjöld, Ekstedt, & Lindwall, 2010); and nursing home residents (Franklin et al., 2006; Pleschberger, 2007). The latter two studies conducted in nursing homes were outside the United Kingdom, and participants were all residents at the end of life, which does not reflect the views of all nursing home residents (Franklin, 2006; and Pleschberger, 2007). Of the aforementioned studies all were qualitative, and only two were conducted within the United Kingdom (Baille, 2009; Woolhead, et al. 2004).

In nursing homes, research has found that residents at the end of life were particularly vulnerable to loss of dignity due to their increasing dependence and loss of control over their bodies (Franklin, 2006). Of importance to nursing home residents at the end of life was a sense that they had achieved in life, had social support, and were not a burden (Pleschberger, 2007). Residents at the end of life felt their dignity was violated when nurses abandoned them, acted indifferently, and didn't approach them as adults. Heijkenskjöld and colleagues (2010), found that nurses who compromised the dignity of patients had flawed ethical values and failed to take responsibility for the dignity of those in their care. In contrast, some nurses had the capacity to see and the courage to prevent others from violating their patients' dignity (Heijkenskjöld, 2010): in practice this may involve whistleblowing on others. This highlights a need to understand what it is that distinguishes one nurse from another in their capacity to recognise such malpractice in care, and what may prevent them from intervening where patients' dignity is compromised.

More recent studies in care homes include action research (Gallagher et al., 2017), cross-national empirical analysis from family caregivers' perspectives (Naden et al., 2013), and a qualitative literature review of dignity from nurses' and

carers' perspectives (Sanakova & Cap, 2019). As this thesis does not focus on the perspectives of family caregivers a review of Naden's paper is not included other than to say the findings of these three studies suggest that perspectives of dignity were generally consistent across all groups regardless of context. Sanakova's (2019) literature review findings from nurses' perspectives suggest dignity thrives where residents are involved in decisions about their care, seen as unique individuals, where good communication and residents' privacy is upheld, and through working culture and environment. From residents' perspective there were six elements to dignity; communication and identity, autonomy and control, privacy, care and comfort, and relationships. In each case the latter was the priority with nurses placing greatest emphasis on 'work culture and environment', and residents prioritising 'relationships'. This may indicate that nurses had busy work schedules and felt time constrained, which is consistent with findings of a lack of dignity conserving care within a hospital culture of care that was both rationalised and under-resourced (Francis Report, Department of Health [DOH], 2013). Also, by prioritising their role as patient advocate nurses positioned patients as passive and lacking a voice, which reflects the position of power the health professional is widely considered to hold in their relationship with patients (e.g., Crossley, 2000; Foucault, 1982). This supports early findings that poor health professional communication with care recipients is common, particularly with older people and people with dementia (e.g., Adelman et. al., 1991; Crossley, 2010; Crotty, 1985; Davies et. al., 2007; Department of Health [DOH], 2013).

Such disparities in the perceptions of dignity between health professionals and those in receipt of care may compromise the delivery of dignity conserving care in practice. However, both nurses and residents identified residents' privacy

and communication as key aspects of dignity (Sanakova, 2019). Action research conducted by Gallagher and colleagues (2017), found ethical leadership is key to creating space for communication between staff and residents and/or their relatives to promote residents' dignity in care homes. Gallagher (2017) also found participation in action research increased staff enthusiasm, promoted partnership and a sense of being valued, and empowered care givers and care recipients. This suggests action research may enhance the communication and partnership (relationships) nurses have with care recipients in order deliver dignity conserving care that aligns with the needs of older care home residents.

### **Perceptions of 'care'**

Similar to the concept of 'dignity', there is a lack of understanding of or agreement on a definition of 'care' within the care-giver/care-recipient relationship. Tronto's Ethic of Care (1993; 1998) constructed care as both a disposition of concern (ethical principles/values) and the action we take as a result of these concerns (moral care giving in practice). In Tronto's theory of care there are four phases, first 'Caring about', second 'Caring for', third 'Care-giving', and fourth 'Care-receiving'. A response to the care received completes the cyclical process. The cycle then continues, whereby the care-recipients' response to the care they have received requires further attention from the care-giver. Tronto suggests that conflict is inherent in care-giving because the care-giver must balance their own needs with the needs of care-recipients in order to ensure the care-giver is able to maintain the cycle of care without compromising their own health and wellbeing. As previously outlined in Chapter 1 (Contextual Review), there are also a number of models of care that aim to provide a framework for the delivery of care in practice (e.g., Brown, 2008; Chochinov, 2007; Kitwood, 1997; McCormack., 2006; Nolan, 2006)). Central to these models

is the idea that dignity conserving care requires that a positive relationship exists between the care-giver and the care recipient within a nurturing environment.

One reason neglectful care exists in nursing homes may be because there is very little literature informing our understanding of such environmental influences on care from the perspective of nursing home staff and residents. A review of the literature identified only three such studies. The first explored 'care' from the perspective of residents (Persky, Nelson, Watson & Brent, 2008), the second included nursing home residents and care-giving staff (Tuckett, Hughes, Schluter & Turner, 2009), and the third included nursing home residents only (Aventuro, 1991). Persky and colleagues (2008) aimed to establish quantitatively how residents in assisted living facilities in the USA prioritised care staff behaviour. Residents scored nurses' technical competency (instrumental activities) higher than humanistic caring (expressive activities), but there was a significant difference between genders in their perception of caring, which was attributed to the difference in communication styles and interpersonal processes between men and women. It also reflects the gender balance of the study that had more male participants (Marini, 1999), which is not representative of residents in nursing homes in the United Kingdom, where there are three women for each man aged 65 and over (Office for National Statistics [ONS] 2014).

Tuckett's (2009) survey of thirty-seven residential care residents and ninety nurses also found a discrepancy between what residents and nurses considered important with regard to care. Residents considered the questionnaire subscale 'Comforts', 'Anticipates' and 'Trusting relationship' to be significantly less important than nurses. Tuckett also found that the 'Monitors and follows through' subscale was most important to both residents and nurses in this study, and

residents also prioritise the subscale 'Accessible', whereas nurses prioritised the 'Comforts' subscale. The disparities here suggest nursing home staff may not have been 'accessible' or have met the on-going ('follow through') needs of residents. Nurses suggested that the quantitative instrument used in the study did not reflect the aged-care setting due to its emphasis on medical discourses of chronic illness and sickness in relation to care of older people, which supports previous findings (Chochinov, 2007). Nurses also felt older residents with cognitive, mental or emotional impairment would not relate well to the instrument, which supports previous findings that quantitative measures may marginalise the voice of this cohort (e.g., McIver, 2005). Of these quantitative studies none was able to determine what influenced nursing home staff and residents to have different care priorities: such understanding is best explored qualitatively.

A review of the literature found few qualitative studies, one of which explored what care meant to twelve participating nursing home residents in the United States of America using observation and interviewing (Aventuro, 1991). Findings suggested that residents wanted to be listened to, to feel cared about, to care about themselves and to take care of others; had a unique way of thinking about care and establishing caring relationships; and were accepting of the fact that they had to receive care. Overall, Aventuro found that caring interactions and meaningful contact between nursing staff and older residents was infrequent. Of concern is that the care delivered conflicted with the expressed care needs of nursing home residents, and therefore represents a shortfall in the delivery of what is perceived by residents to be appropriate care.

In conclusion, regardless of methodology used, all of the studies presented here found a discrepancy between care-givers' and older care recipients' perspectives of dignity' and 'care', which is likely to result in delivery of inappropriate care. Of these studies none identified why such discrepancies in care exist. To contribute to answering this question I now present the method of data collection and analysis I used during my focus group study that explored nursing home staffs' perceptions of care. The findings are discussed in chapter 6 alongside residents' perspectives from study 3 (Chapter 5) taking into consideration contextual influences identified in observation study 1 (Chapter 3).

## Method

### Ethical Considerations

Sheffield Hallam University and Local Authority ethics approvals were obtained for the overall Doctorate in Philosophy (PhD) research (see appendix 0.1 to 0.4). Study specific ethics documents are included in the procedure section.

### Participants

I conducted a focus group with a purposive sample of volunteer staff recruited across all three participating nursing homes. Recruitment of volunteers involved placing advertising posters (appendix 2.1) on staff notice boards and sending research information sheets (appendix 2.2) and volunteer slips (appendix 2.3) to all nursing home staff in their monthly pay packets. Volunteers were each offered a £10 high street voucher funded by Sheffield Hallam University as further incentive to participate. Volunteers completed a volunteer

slip that was either posted back in a stamped self-addressed envelope, or collected by me from a secured box in each of the three participating nursing home reception areas. All volunteers were from a single nursing home. I contacted each of the seven volunteers by phone, and most opted to participate in the focus group when on duty in the nursing home. Therefore, I obtained volunteers' consent to disclose their participation to the nursing home manager in order to make arrangements for them to be released from duty at mutually convenient time. The nursing home manager arranged a suitable private room within the nursing home in which to conduct the focus group and gave permission for all 'on duty' participants to attend the focus group during the quiet afternoon period between 14:00hrs and 15:30hrs.

Initially there were seven volunteers for the focus group study (six female and one male) comprising four Care Assistants, two Registered Nurses, and one Activities Coordinator. On the day of the focus group two female Care Assistants were unable to attend due to staff shortages, and the male Care Assistant dropped out due to personal circumstances. The final focus group comprised of four females and included one Care Assistant on day shifts, one Activities Coordinator who worked Monday to Friday 09:00hrs-17:00hrs, and two Registered Nurses of whom one worked day shifts (between 8:00hrs-20:00hrs) and the second night shifts (between 20:00hrs-08:00hrs) (see table 3: focus group participant information). Both Registered Nurses attended while off duty: the night duty Registered Nurse came in from home, and the day duty Registered Nurse staying after her morning shift had finished. Participants were aged between 21 and 57 (mean age 39). Participants had worked between 23 months and 59 months



in this nursing home (mean 40 months) and between 23 months and 120 months in nursing homes overall (mean 72 months). All participants were White British, two identified themselves as Christian and two specified no religious allegiance.

**Table 3: Focus group with nursing home staff - participant information**

	Participant No and Pseudonym			
	P01 - Mary	P02 - Josie	P03 - Amanda	P04 - Lisa
Sex	Female	Female	Female	Female
Age (years)	56	30	21	27
Job Role	Registered Nurse (Days)	Registered Nurse	Care Assistant	Activities Coordinator
Overall Experience (years and months)	30 years as a RN	10 years as RN in nursing homes	3 years 4 months	4 years 11 months
Total number of nursing homes worked in.	1	2	3	1
Years & Months in Current Role (years and months)	1 year 11 months	3 years	Not specified	4 years 11 months
Race	White UK	White UK	White UK	White UK
Religion	None	None	Christian	Christian
Highest Qualification	First Degree	First Degree	NVQ Level 2 1-5 GCSE's	First Degree
Photograph or Object brought to focus group	Photograph (on telephone)	Forgot to bring anything	Photograph (on telephone)	Potted Begonia

## Procedure

Participants took part in an audio and video recorded focus group where I used photo-elicitation and object elicitation methods (described below). The principle of both methods is that by selecting an object or a photograph taken by them, participants become more engaged with the topic, which facilitates the articulation of their views about complex subjects such as 'care' and 'care giving'.

These methods use objects or photographs as conduits between participants' inner cognitive and emotive views on a subject and the articulation of those views.

### ***Rationale for using Photo-elicitation and Object-elicitation data collection methods***

Photo-elicitation: was developed within community based participatory research by Caroline Wang and colleagues in the 1990's. Primarily its aims were to engage people through images in the identification and discussion of the strengths and shortcomings of communities, increase knowledge about such issues, and ultimately inform policy (Wang & Burris, 1997). I chose photo-elicitation as this thesis also aims to establish care workers' positive and negative views of care within the nursing home community and add to existing knowledge with a view to informing care policy. Harper (2002) suggested that the use of photographs in research interviews triggers individual workers from a diverse range of job roles to adopt a different view their social world, and facilitates the deconstruction of their individual phenomenological assumptions: which is also a desirable outcome of the present focus group study. In further support, photo-elicitation has more recently been adopted to successfully explore a range of concerns of social injustice and public health issues (see literature review by Catalani & Minkler, 2010). The photo-elicitation method required participants to bring a photograph taken by themselves as a catalyst for talk about the subject in question. This corresponded with Moscovici's (1961) social representations theory, which suggested that when ascribing meaning to abstract phenomena, such as 'care', we may use existing objects to integrate and transform them by presenting them through something tangible, such as a photograph.

Object-elicitation: follows the same principles as photo-elicitation in this respect but instead provided participants with the option to select an object that

they felt was representative of the subject of discussion (Kompter, 2001). Encouraging participants to choose an object was based on Goffman's (1971) idea that objects are 'tie-signs' that represent social bonds. Such bonds originate from human relationships between people known to one another, which Goffman refers to as anchored bonds. As the aim of the focus group was to explore 'care' from the perspective of staff in the context of a nursing home community (where participants have social bonds with residents and other staff that are known to them), I considered the use of objects to stimulate participants' talk about care to be appropriate. Further, the method is particularly useful in exploratory research as it requires minimal input from the facilitator of the discussion thereby reducing the researcher's influence on participants' accounts.

### ***Conducting the Focus Group***

I conducted the focus group based on guidance within the literature (Silverman, 2004 & 2005). The focus group took place in a private, quiet and informal space within the nursing home. Video and audio (dictaphone) recording equipment were placed discretely to ensure that participants were not distracted by it. Video recordings facilitated my accuracy and recall during the orthographic transcription process. On arrival for the focus group, I invited participants to sit wherever they preferred in a pre-arranged comfortable seating area, and offered refreshments (tea and biscuits) to promote a casual and relaxed atmosphere. Each participant read through the information sheet (appendix 2.2) and all were happy to provide full written consent (appendix 2.4) and fill out the demographic information form (appendix 2.5). Once I obtained full informed consent, I commenced the focus group by inviting participants to explain how the objects they had brought represented 'care' to them, which was effective in stimulating open and often reflexive talk between participants about what care meant to

them. Throughout the focus group I remained deeply attentive to the participant-led conversation to ensure that it remained focused on the topic of interest. I had a prepared focus group topic guide and prompts (appendix 2.6) that were largely not required as participants self-managed their talk with little if any intervention from me, the researcher. The focus group discussion was restricted to one hour by the need for the Care Assistant to return to work.

The 'Information for Participants' sheet that volunteers received in the recruitment letter requested participants bring to the focus group either an object or a photograph that represented what 'care' meant to them. The Activities Coordinator brought a potted plant (a photograph of this object is enclosed, see appendix 2.7). The Care Assistant brought a photograph of herself with a recently deceased resident in which they were holding hands with each other and smiling. The photograph was on her mobile phone therefore it was not possible to make a copy of the photograph. Similarly, the Registered Nurse working on days brought a photograph of residents she had escorted on a social visit. The Registered Nurse working on nights forgot to bring anything. Additionally, during the focus group the Care Assistant said that she would have brought a poem with her named 'The Crabbit Old Woman' that is also referred to as 'Mattie's Poem' (a copy is enclosed in Appendix 2.8). I (the researcher) mentioned I had a copy of 'Mattie's Poem' poem with me in my research file because I had seen it (and a nurse's poetical response) on the nursing home notice board during my ethnographic observations. Subsequently the Care Assistant was encouraged by other participants to read out the poem during the focus group, which she did.

At the end of the focus group, I verbally debriefed participants as a group and gave each participant their own hard copy of the debrief sheet (see appendix

2.9) and a £10 high street voucher for taking part. Immediately following the focus group, I transferred the audio and video recordings to an encrypted university pen drive, and deleted the data from the video equipment and Dictaphone. The following day I transferred all data to a secure password protected university hard drive to maintain confidentiality of participant data. Electronic data files were given a unique code to maintain participant anonymity. I transcribed audio recordings of the focus group verbatim using basic orthographic transcription (see appendix 2.10

for transcription guidelines). All identifying features such as names and places were given pseudonyms to maintain participant confidentiality. Extracts of transcribed data presented in the findings section are annotated according to orthographic transcription conventions.

### ***Study-specific Ontological and Epistemological Considerations and the Analytical Process***

In keeping with the Critical Realist position of this thesis (Bhaskar, 1975b; and Bhaskar et al., 1998) the staff focus group data was analysed using Thematic Analysis (in accordance with Braun, 2006; and influenced by Lawless, 2019) that is detailed for this study in Chapter 2, 'Overall Methodology'. In summary, I adopted an inductive approach to Thematic Analysis throughout the coding process, with codes being derived from the data itself rather than through imposing existing theory or hypotheses on the data. I conducted a latent Thematic Analysis which involved deciphering the extra-discursive features attended to by individuals within the data that gave meaning to participant's accounts of 'care'. I paid particular attention to elements of embodiment, institutions and materiality, and considered participants' talk about what care meant to them and how they

orientated their accounts in relation to the extra-discursive features that I had identified in the observation study and literature review data (see Chapter 3).

As participants' talk was saturated with references to the emotive nature of care, I drew on Cromby's work on embodiment in relation to feelings (Cromby, 2007; Cromby, 2011). Building on the work of Ruthrof (1997) and Merleau-Ponty (1962), Cromby (2007; 2011) suggests that embodied experiences (signs) are meaningful in their own right, but are also interpreted alongside other signs, such as linguistic signs. He posits that feelings are socially influenced, experienced and expressed in accord with social norms that determine when, where, and how emotions, such as happiness and fatigue, should be enacted. Thus, thought consists of two embodied and socialised elements, first, language, and second, affect and feeling. Cromby suggests feelings rather than emotions or affects provides the most useful analytic approach as it places a psychological emphasis on experience because feelings are linguistic primes. Feelings fall into three categories, first 'Emotional feelings' that have a somatic component such as fear, shame, sadness; second, 'Extra-emotional' feelings such as sensations of touch, fatigue, illness; and third, 'Feelings of knowing' such as gut reactions based in part on past experience that have a relational significance and are aroused during interactions, such as those between a care-giver and care-recipient.

Present focus study participants also referred to knowledge in their talk: therefore, I drew upon Foucault's broader discursive approach to representation as the historically grounded production of knowledge as power (Hall, 2013). Due to the prevalence of intergroup social comparisons within participants' talk, the analysis has taken into consideration the positioning of Tajfel's (1979) 'integrative theory of intergroup conflict (ITIC).

**Table 4: Speaker identifier in the data analysis process and presentation of data extracts**

<b>Participant No.</b>	<b>Speaker Pseudonym</b>	<b>Participant Job Role</b>
P1	Mary	Registered Nurse - daytime shifts
P2	Josie	Registered Nurse - night shifts
P3	Amanda	Care Assistant - daytime shifts
P4	Lisa	Activities Coordinator - Mon-Fri, 9am -5pm
Interviewer	Int	

My immersion in the data started during my transcription of the focus group audio data and continued during my systematic and rigorous reading and re-reading of the transcribed data corpus. In the second 'coding' phase I generated 156 initial codes that comprised of words, sentences or conversations between participants. I retained the origin of each coded extract by preceding it with the participant number (P1; P2; P3 or P4) or 'INT' for the interviewer, followed by the transcript line number (e.g., L24-25) in which it appeared, alongside a speaker identifier (pseudonym) for each participant (e.g., Mary) (see table 4). Where extracts were

conversations between multiple participants the line numbers omitting the pseudonyms was used for simplicity: individual speakers in such conversations are identifiable by their participant number.

I then collated coded extracts in an excel spreadsheet (see example appendix 2.11). In phase three of the analysis, I organised extracts of text into 20 groups meaningful to the research topic such as staff attitudes, beliefs and values; contextual information; participant interactions; working practices; physical resources; social aspects of care; financial influences; ideas for change; and perceptions of older people. I coded some extracts into more than one of these groups where applicable. To facilitate the identification of coded data I allocated grouped data a different colour according the particular aspect of 'care' they related to, such as physical care, psychological care, social care, self-care. Colour-coded group data was then sifted, re-organised and merged to form six initial themes that were representative of the main topics found in the data. In the final stage I organised initial themes into higher order categories that comprised of three main themes that represented how participants positioned themselves and others in relation their perceptions of care and the role of care-giver.

### Analysis: Presentation of Findings

The first theme (Obligate Carer) outlines how participants' personal construction of care conflicts with the care ideology of the institution in which care is delivered. It also highlights the emotional nature of care work and the challenges faced in balancing participants' own needs with those of residents.



The second theme (Resentful Carer) attends to the value laden nature of care work. Here participants' desire to comply with their self-identity as a caring person and professional care-giver (as defined in theme 1, 'Obligate Carer') conflicted with their perception that their role as care-giver was undervalued and unheard, and that they were overworked.

The third theme (Constrained Carer) identified the embodied, material and structural constraints participants encountered in the delivery of their ideology of care in practice. It also highlights the conflict participants encountered when attempting to reconcile their inability to deliver care in accordance with their personal philosophy of care.

## Theme 1 – Obligate Carer

Existing literature proposing theories and models of care (see Chapter 1) suggest that care requires investment by both the care-giver and the care-recipient, and is therefore relational in nature. In the present theme, participants' perceptions of what care represented to them at a personal and professional level are presented.

### ***Sub-theme 1.1- Constructions of care: The 'vocessional' care-giver dichotomy***

In their construction of what care meant to them, participants drew on the photographs or objects they had brought with them to the focus group. First, Mary made clear that to her caring was a vocation rather than just a job. It was about care-givers having the "*inclination to go and do it in their own time*" (L24). For Mary caring was about having the innate disposition and desire to connect with individual residents at a personal level (this is discussed in greater detail in Theme 3, sub-theme 2: Personal Constraints). She constructed herself as both

vocationally and dispositionally inclined to care, and reinforced this position by presenting a photograph of her taking residents out socially in her own time (Mary: L19-21). In accordance with Goffman's (1971) tie signs, the photograph provided support to Mary's positioning and construction of herself as a caring person by materially anchoring her claim.

*P1 which sort of brings me to mi caring thing because somewhere in here (refers to mobile phone) I've got a lovely picture of one of our residents (.) sitting in the erm (City Centre) Gardens having had coffee down at erm the (City Centre) Gallery's Café and just before we went up on the wheel (.) and to me that's the sort of thing we should have time to do within the working week (.) but unfortunately they don't get that sort of stuff unless you get somebody that's got enough time (.) and spare income I suppose on their hands as well as the inclination to go and do it in their own time (.) so (.) any comments folks? (3) perhaps I should say that my background was actually mental handicap before I was a general nurse (.) so I've got er quite a long history of wanting to (.) care as opposed to cure (.) treat*

*(Mary: L18-L26)*

Although Mary had a long career as a nurse, for her, caring went beyond attending to the physical aspects of health and illness she had learned during her medically-driven training. Caring was about connecting with residents at a personal level outside of the contractual obligations of her job role (L18-22). However, there was conflict in Mary's positioning of herself in her role as care-giver. On the one hand Mary presented herself as a professional care-giver by drawing on her extensive experience and knowledge as a nurse to position herself as credible to comment on the subject of care; "*perhaps I should say that my background was actually mental handicap before I was a general nurse*" (L24-25, Mary). Such positioning of herself as a Health Professional and thereby credible suggests that Mary had embodied the idea that medical knowledge equates to power (Foucault, 1982). In contrast, within the same sentence Mary also alluded to her desire to care and positioned herself as a 'vocational' carer;

*"I've got a long history of wanting to care as opposed to cure, treat"* (L26). This suggests that for Mary the care-giver role was dichotomous as it involved both vocational and professional identities. I refer to this as the 'vocessional' carer identity. The tension that existed between Mary's personal construction of what care meant to her (values) and her 'professional' capacity to both deliver and comment on care in practice (moral care-giving), resonate with the conflict inherent in Tronto's Ethic of Care (1993;1998).

The distinction Mary made between caring and merely treating illness or attending to the physical needs of residents was shared by all participants, including those that were not medically trained. For example, Lisa the Activities Coordinator stated; *"I think care's holistic, you need to be holistic when you look at how you care for someone. It's not just treating them with medicine; it's not just, yeah. It's not just giving them something to do it actually; to care for someone is to care for every aspect, of their life really"* (Lisa: L29-L31). This suggests a shared rejection of medically reductionist approaches to care among participants regardless of their discipline or formal care-giving role.

To further support this positioning of care as non-dichotomous Lisa later presented a potted begonia which she metaphorically used to depict what care meant to her (Lisa: L837-865). Again, this provided material anchoring for Lisa's positioning of care as holistic in nature and as going beyond meeting the physical care needs of residents. Holistic care meant nurturing (patiently loving) residents over time, which provided the conditions for residents to flourish, to gain a sense of purpose, and to feel needed.

*P4 when I'm thinking about care (.) I'm thinking about (.) so when a resident comes in (1) I kind of like (.) you don't necessarily see anything that's beautiful around them (.) or about them (.) you just kind of they come in and (.) may be really unresponsive*

P3        *like a shell*

P4                *yeah (1) perhaps we view people like a shell we don't understand the wealth of experience that they've got (.) the gifts that they've got that (.) just who they are (.) but I I felt like as the residents watered this begonia (.) and it you know we still didn't see any response for a year perhaps the way that we interact with the residents and love and care for them and nurture them (.) then you do see results (.) and I think we should do it even if the results aren't a beautiful flower (.) so if it's no something that's obvious (.) but often with the residents the more you love and care for them and the more that (.) yeah (.) you help them to (.) to grow and to get (.) have confidence that they do flourish*

P1                *hmmm*

P4                *and I've just seen with quite a number of residents like (.) like [says the names of two female and one male resident] (.) the more (.) that you put into them the more confident they get and the more that [they*

P3                                *you get out of them*

*(L837-L854)*

Lisa felt that emotional investment helped residents gain confidence and resulted in residents' reciprocation by giving back to others (residents, staff and visitors) in the nursing home community. Also, Lisa suggested caring required that staff connect emotionally with residents and recognise the life narrative of residents. Over the course of the focus group, this view was shared by all participants. For instance, Amanda referred to a poem that summed up what caring meant to her. The poem named 'The Crabbit Old Woman' or 'Mattie's Poem' (appendix 2.8) was a written depiction of an older person's perspective of being unrecognised as a person and objectified by the nurses caring for her. Amanda read this aloud to convey participants' collective sense that care required understanding of the whole person over time and residents' sense of identity prior to nursing home life. As if to support that she was a good care-giver Lisa supported that they (participants) applied their philosophy of care in practice: for example, through the use of photo-boards of each resident's life-story within the nursing home (Lisa: L918-924).

P4 *we thought it was really important to have photos of the residents when they're younger (.) around (.) and we're going to take these boards up onto the floors so that it's just a good reminder for me and the carers (.) and for other relatives and for other residents (.) who look at a resident and (.) and just see an old lady (.) it's good for them to remember that they were a nurse they were (.) a (.) you know what they did they were in the army (.) you know a mother (.) they went on holidays they enjoyed things the same way that we do and just that wealth of like history that they've had that has brought them to that point and to have compassion for people really*

(Lisa: L918-924)

Such biographical approaches have been found to promote the development of relationships between Health Professionals and older hospital patients (e.g., Clarke, Hanson & Ross, 2003) and are therefore in keeping with relational models of care. Again, participants' construction of care and care-giving was consistent with the relationship/person centred care models previously described in Chapter 1. In particular Lisa's account made reference to: all of the senses (security, continuity, belonging, purpose, achievement and significance) in Nolan's (2006) Senses Framework; social and human dignity outlined in Jakobson's (2009) Taxonomy of Dignity; recognition, respect and trust identified in Kitwood's (1997) Person Centred Care; and met the requirements of compassion within Chochinov's (2007) Dignity Conserving Care model. The necessity to understand residents' life stories was also aligned with Tronto's (1993; 1998) ethic of care, where care givers are required to care about as well as care for care-recipients. Although all participants' accounts acknowledged the psychosocial aspects of care, Lisa's particular emphasis of relational aspects of care may have reflected that, in contrast to other participants, she felt more obliged to focus on meeting residents' psychosocial rather than physical care needs in her formal role as Activities Coordinator.

### ***Sub-theme 1.2: The sacrificial and the rewarding nature of care-giving***

Participants' talk revealed that when residents engaged relationally with them and others in the nursing home, staff felt rewarded for the care they had invested. This two-way nature of the care-giver/care-recipient relationship was summed up by Mary when she looked at the photograph Amanda had brought to the focus group that represented what care meant to her (L635-644).

*P3 it's a picture of myself and a resident who's passed away now but is what I think care is maybe (.) you've seen it 'aven't yer?*

*P4 yeah it's my favourite photo*

*P1 is that the one you sent me?*

*P3 yeah (passes phone to P1 to look at photo)*

*P1 it's a lovely pic that (1) yes (.) that is about caring*

*P4 that is it (.) that's*

*P1 it's a genuine warmth and affection on both of their faces (.) a relationship that is a two-way relationship not a one way relationship*

*P3 Awe I'm all teary heh heh*

*(L635-L634)*

Here, participants' accounts of care-giving within the nursing home environment were in keeping with the reciprocal nature of relationship-centred care outlined in the literature (e.g., Tronto, 1993; 1998; McCormack, 2004). Additionally, participants also felt that the two-way nature of the caring relationship extended beyond their relationship with residents to their peers, which is consistent with Nolan's (2004) idea that therapeutic nursing, particularly for older people, requires a network of relationships. Peer relationships were evident in the following extract where Mary and Amanda considered the current nursing home manager to be caring because, like them, she gave beyond her contractual obligations. For example, in the following account of participants' talk

they described how the manager had worked “*like for a week*” (Amanda: L377) in extreme weather conditions, ‘*struggling*’ (Mary: L380) to ensure staffing levels were met (L377-383 below).

*P3 when it was snowing as well she (nursing home manager) slept here didn't she*

*P1 hmm hm*

*P3 like for a week*

*P1 and she fetched everybody that was struggling in her little four bi four*

*P3 I think that was to prove a point that you can get here no matter what the weather*

*All laugh*

*P1 well I don't know because she knows she's in a possession of a four bi four*

*P4 she was very (.) very appreciative wasn't she*

*P1 but what really bloody annoyed me about that winter was the RGN (RN) who lives next door or something or on the same street as the carer*

*P3 oh yeah*

*(L373-L383)*

When staff made an extra effort to get into work they had been rewarded by the manager's appreciation, which supports findings that nursing home staff have higher job satisfaction (Castle, 2006: Gallagher, 2017) and more effective communication (Gallagher, 2017) where management is perceived to be good. This appeared to further re-enforced participants' personal care values that required personal sacrifice to meet residents' care needs. Co-workers' compliance with these group norms was greeted positively by participants, whereas non-compliance was scorned upon. This was evident where Mary positioned the Care Assistant who made it to work despite deep snow as caring, but depicted the Registered Nurse who didn't make it to work as uncaring (L388 below). Mary and Josie, both Registered Nurses, positioned the absent

Registered Nurse as different to them: instead, they portrayed her as materialistic and selfish (L391-L397). They intimated that placing one's own needs before residents' needs represented an uncaring disposition.

*P1 and the carer got here and the Registered Nurse didn't (.) bitch*

*All laugh*

*P1 but anyway*

*P2 (still laughing) her with the excuse why should I risk damaging my car*

*All laugh*

*P1 (still laughing) such a caring soul (laughs) (in a mock posh voice) she cared very deeply about whether she'd got freshly applied lip gloss on or not (.) but then I suppose when you've got so many naturally occurring disadvantages to your appearance I suppose you have to be a bit (.) er (P2,P3 and P4 slightly embarrassed laughter) (.) paranoid about improving on nature I suppose*

*P4 hee hee (.) we're slightly going off at a tangent aren't we*

*(L388-398)*

Here, participants' talk constructed personal sacrifice and a sense of camaraderie among care workers as implicit to care. Such peer pressure to meet these high expectations may increase nursing home staffs' level of stress and ultimately lead to burn-out (Cohen-Mansfield, 1995). Participants positioned the Registered Nurse who failed to demonstrate such behaviour as different to them, therefore placing her outside their group values. This aligns with the positioning of the 'in-groups' and 'out-groups' of Tajfel's (1979) integrative theory of intergroup conflict (ITIC). However, there appeared to be a divide within the 'in-group' (i.e., present focus group participants) where Mary's negative comments about the absent Registered Nurse's personal characteristics met with uncomfortable laughter of other participants (L389). This suggests Mary's position differed from other participants, and particularly Lisa who distanced herself from Mary's accusatory talk with the diversionary comment "*we're slightly*



*going off at a tangent aren't we"* (L398). This may have been because the aggressive nature of Mary's talk conflicted with Lisa's Christian values. It was also contrary to the definition of a caring disposition that participants had individually and collectively portrayed to each other and to me as the researcher, within the context of the focus group. This again supports the conflicting nature of care outlined in Tronto's 'Ethic of Care' (1993;1998). As if recognising that her talk was not representative of the shared care values of the group, or the caring position that she had personally sought to establish rhetorically, Mary then apologised.

It is plausible that Mary's passionate account reflected her self-identification with the values of the Registered Nurse 'daytime' care worker group. The other Registered Nurse's breach of these values and behaviour therefore resulted in Mary blaming this on the personal characteristics of the Registered Nurse who had contravened them. Such discourse illustrates that participants experienced an emotional tension associated with caring that required commitment to caring for and caring about all those involved in care, including residents and their colleagues. Non-compliance with group norms by some led to intergroup conflict, which is contrary to the promotion of relationship centred care.

Further, the manager had set standards of care-giving that required personal sacrifice. In conjunction with participants' embodied ethic of care 'to give', this placed participants under additional external pressure to compromise their own needs and safety (e.g., to travel in unsafe weather conditions) in order to meet the needs of residents and the demands of their employer, manager, and work-colleagues. This may lead to staff burnout (Cohen-Mansfield, 1995; and Treweek, 1996;2000) and contravened Nolan's (2001; 2004) Senses

Framework that requires that staff should feel free from physical threat. It also supports findings that staff's needs and personhood are not always acknowledged in the context of caring for people with dementia (Kadri et al, 2018). Therefore care-givers' sense of an obligation to give too much, whether internally or externally constructed, led to intergroup conflict that may impair the delivery of relationship-centred care in practice.

### ***Sub-theme 1.3: Camaraderie and dissonance: The collective care conscience***

As if to repair the damage Mary had made (in sub-them 1.2) to participants' collective representation that they, as a group, were good care-givers, Josie, Amanda and Lisa made institutional downward social comparisons between them and other care-givers (L466-478). For example, they positioned hospital and care-workers in other nursing homes as uncaring, and the care as inferior to that provided by them despite "*all of the negatives*" (Lisa: L477-478) they encountered.

*P2 yeah because it's more than meeting basic needs isn't it that's why I like care homes and not the hospital because (.) in hospital it's patch up the immediate problem and then send them on their way (.) and what happens to them after that*

*P3 they don't care*

*P2 is none of your concern and nobody even stops ter (.) think about what happens to them when they are out the door (.) [and*

*P3 cos often they come here like that don't they]*

*P2 and it's not even so much about their medical problems its (.) it's their lives*

*P3 it's their quality of life in't it (.) we're here to improve that or make it as best we can*

*P2 hmm*

*P4 and I think compared to a lot of homes we do a good job (.) like I think we can name all of the negatives of how we feel in this care home*

*(L466-L478)*

In talk people defensively use devices such as downward social comparisons to either self-evaluate, to feel better, or to feel superior to others (Wills, 1981). Additionally, they bolster their individual and collective self-esteem where the reputation of the group is jeopardised: for example, where some group members contravene the established collective group values (Tajfel, 1979). Here, focus group participants' talk served to distinguish their nursing home from the poor institutional care practice depicted in wider society: for instance, that outlined in the contextual review (chapter 1), and media reporting of institutional abuse such as that referred to by Mary earlier in the focus group (L120-125 below).

*P1 The residents feel it as well (.) I mean you look at somewhere like er is it West Staffs that was in the Sunday press recently a public enquiry (.) shock horrors people dying needlessly bla di bla di bla (.) whilst I wouldn't condone it for one second I can see exactly how it's happened (.) because they're permanently running erm wards short of staff than they ought to run and so standards slip (.) er and you become mentally and physically exhausted having to deal with too little*

*(L120-L125)*

Although participants disassociated themselves from such poor care practice as it conflicted with their personal and professional ethic of care, they also acknowledged and empathised with the challenges fellow group members (other institutional care-givers), encountered in maintaining good care in practice. This highlights the tension care-workers encounter between their professional obligation to provide good care, and a sense of professional loyalty to and personal empathy for other professional care-givers who contravene ethical care practice. It also highlights participants' embodiment of wider negative portrayals of care work (e.g., BBC News, April, 2014; CQC, 2014a; CQC March, 2015; CQC

January, 2019), and the defensive strategies staff adopt in order to retain a sense of self-esteem within their dichotomous 'vocessional' care-giver self-identity.

#### ***Sub-theme 1.4: The compromised carer: balancing needs***

Although all participants, and particularly Mary, talked about prioritising residents' needs over their own as integral to care, this presented them with a dilemma because they also recognised that there were limits to what they were able to give without compromising their own health and wellbeing.

*P3 well there's so little time and so much to do*

*P1 which is why I try to every so often (.) I mean I don't over-do it because I know that if I knacker myself out (.) I'm not going to be able to carry on doing it but that's why every so often I will try and take (.) I used to take [says names of three female residents] out (.) [male resident name] is the latest (.) and it's fabulous*

*(L454-L458)*

To maintain her own physical health Mary talked of limiting the amount she gave in order to sustain the close relationship she has built with some residents, which she also benefitted from personally. Such autonomy has been found to reduce the likelihood of care staff burnout (Felton, 1998). Additionally, focus group participants attended to the psychological costs to themselves of investing emotionally in their care-giver role. This is evident in the following extract where Amanda had just shown everyone a photograph she had brought that represented what care meant to her. It was a picture of Amanda with a recently deceased resident. Participants exhibited conflicting accounts of how they felt when residents died.

*P3 Awe I'm all teary (laughs)*

*P4 and it's more it's just really sad because she's passed away (2) isn't it*

*P1 bless her*

*P3 yeah*

*Int and you were talking weren't you about (.) er the grieving for residents (.) but how does that impact on staff as well (.) y'know*

*P4 you're not given time are yer*

*P3 I think it's quite difficult because I sort of wanted to cry a bit and get upset but (.)*

*P1 I was deeply grateful because she went on Josie's shift not mine because I would have been in bits if she'd gone with me*

*P3 yeah (.) I think I would have (.) if that had've (.) had been the case but*

*P1 I'm hoping you weren't in bits on nights (looking at participant 2)*

*P2 [you do get upset*

*P1 I know but I'm hoping you were (1) that particular one (.) you know (.) thank you for (inaudible)*

*P3 I don't know it was a sad time but (.) I think for the residents we sort of had to be strong and (1) don't know really (.) it's strange] I just sort of don't get upset (.) I don't know why (1) but (.) I don't know I do get quite attached to some of them*

*P1 you're bound to*

*P3 but I don't know I just don't get that upset (1) maybe it's just something about me*

*P4 it's difficult (1) no it's not it's because*

*P1 you probably  
channel in another way*

*P3 because I want to (.) I do sort of like want to grieve of them and*

*P4 but you are professional so you're carrying on*

*P3 I don't know*

*(L640-L665)*

Mary "was deeply grateful" that Josie was on duty rather than her when the resident in Amanda's photograph had died, which conflicted with Mary's positioning of herself as wanting to be there for residents. Yet Mary's distress at the death of the resident also supported that she invested emotionally in her relationship with some residents. Similarly, Josie claimed she didn't get

distraught, but in the same sentence said that she became “*really upset*” when she was unable to meet the end-of-life care requests of residents within her formal carer role (L670-671). Amanda also talked of feeling “*all teary*” (L644) at the death of the resident in the photograph she had brought, yet couldn’t understand why she didn’t get upset when residents died. Although Amanda wanted to grieve for residents, she also positioned herself as having to be strong for residents (L659), which Lisa suggested was implicit to their role as professional care-givers (L664 Lisa). In their talk participants rationalised for themselves and attempted to justify to one another and me (as researcher) why they disengaged emotionally within their relationship with residents and their relatives at the end of life. In accordance the suggestion that feelings are embodied, experienced and expressed in accordance with social norms (Cromby, 2011), participants had suppressed their own feelings in order to adhere to socially constructed expectations of the professional care-giver role.

Participants’ suppression of their feelings closed down the opportunity to connect with the emotional work they considered to be necessary in care-giving. Detachment is evident in staff experiencing occupational stress (Cohen-Mansfield, 1995) and is commonly adopted by Care Assistants as a buffer against emotional stressors associated with caring and death of older adults (Teresi, 2001). It is also representative of disenfranchised grief (Doka, 1989), and complicated grief (Holland et. al., 2009) where staffs’ grief is not openly acknowledged, socially validated, or allowed, which results in the individual experiencing a grief reaction without the right to social sympathy or support. Exclusion from mourning applies to both the work place, and to health care professionals (Bento, 1994). Disenfranchise grief may negatively impact on the wellbeing of professional care-givers (DiBiase, 2009) as mourning is

facilitates the transition to life without the dead person (Vizedom, 1976), and failure to mourn may result in depression (Zhang, 2008). Inability to mourn was evident where participants found it difficult to reconcile the conflict between their personal and professional carer identities or where they gave too much and therefore compromised their own needs.

Such conflict resulted in a tension between participants, for example, where Mary struggled to negotiate her grief at the death of a nursing home resident, she expressed jealousy that her colleague Lisa was able to manage her grief due to her spiritual beliefs, which Mary did not have.

*P4 there's a tension about being a Christian but also (.) at the end of the day I can just pray and give it to god and I've (.) a burdon's took off me so I don't have the guilt*

*P1 that's why I envy you because being a dyed in the wool humanist I don't have anybody to unload it on (.) the buck stops with me*

(L1033-L1036)

Mary also envied Josie who had more time to engage at the relational level with residents when working at night than she did working on days saying, "*it must be an absolute luxury it must be lovely*" (L88).

Because Mary did not have access to these resources (faith and time) she felt less able balance her needs with those of residents and the demands of her job role. According to Tajfel (1979) such perceived inequalities may have the potential to cause inter-group conflict between co-workers. As participants' care beliefs corresponded to a relational model of care that necessitates team working and cohesion, such inter-group conflict is un-conducive to the delivery of relational care in practice. However, Tajfel also theorised that the shared care beliefs of a group provide a buffer to inter-group discord. As sub-theme 2

highlighted that participants shared similar care values, this may have provided a sense of cohesion between participants, and thus a buffer.

***Summary of theme 1:*** In the present theme, participants' perceptions of what care represented to them at a personal and professional level were presented, and corresponded with a relational approach to care through a desire to connect socially and emotionally with residents. In contrast, staff constructed their formal role of care-giver within the nursing home as one that required them to be professional, objective, and disconnected from residents. For participants this dichotomous care ethic created a tension as they endeavoured to balance their personal and professional care-giver identities.

## Theme 2 – Resentful Carer

There is increasing concern about poor care practice by care workers in both the hospitals (e.g., Department of Health [DOH], 2013) and long-term care institutions (e.g., Kenyon et al., 2011). There is also concern over the increased number of care workers that are either absent from work or leave the care profession permanently due to burnout (Maben, 2007). Burnout has been described to be the result of a loss of spirit in otherwise motivated and committed individuals, and from an existential perspective lies in people's need to believe that their lives are meaningful and the things they do are useful and important (Pines, 2002). In the present theme (theme two) I outline participants' accounts of what influenced them to feel either motivated or unmotivated to 'care' within the nursing home context.



### **Sub-Theme 2.1: Undervalued**

Of note in participants' accounts was a sense of feeling undervalued by society as a whole, and by their employers. This conflicted with participants' personal self-identity as a care-giver and their collective belief that caring was important and meaningful (views which were reflected in Theme 1: Obligate Carer).

First, participants resented that management at Head Office did not acknowledge that they (permanent nursing home staff) were generally better qualified and experienced to deliver quality care to residents than agency (temporary) workers. This resentment was compounded by the fact that agency workers received greater remuneration than participants. Participants felt this undervalued the contribution they and other permanent staff made to the nursing home community.

*P3 It's frustrating for the other staff that are getting paid less than the agency staff and the agency staff don't know what they're doing (.) they don't know the residents and they're just wandering round aimlessly (.) and you're having to tell them and explain to them what you do and (.) we've worked short often and said to (the manager) sort of don't bother getting agency because we'd rather do it ourselves than explain to them (.) cos by the time we've explained we might as well have done it ourselves (Josie: L251-256)*

*P1 I mean you get good ones you get some lovely ones that you're really glad to have and what you welcome back when they come again (.) the trouble is you don't know er in advance what you're gonna get and I've known a situation where one particular carer was absolutely banned from working here ever again until we're desperately short and that was all that was on offer so we got her anyway (Mary: L257-261)*

Consequently, as seen in the above examples, participants experienced a tension between their sense of loyalty to the nursing home hierarchy as an employee, and their resentment that their employer placed greater value on outsiders, who contributed less to the organisation than them. Although

participants perceived care work as vocational, they also positioned it as professional and occupational and resented not being fairly remunerated by Head Office for their contributions as a worker. Dissatisfaction with remuneration and working conditions among participants is consistent with previous findings among nurses and care workers (e.g., Coward, 1995; Harris-Kojetin et al., 2004; and Equality and Equal Rights Commission, 2011). When considered alongside balancing their own needs with those of residents, the cumulative effect can result in stress, burnout and high staff turnover and absenteeism (Castle, 2010).

Despite sharing the same role as care-giver, participants portrayed temporary care workers from outside the nursing home in a negative light. Such disassociation with others that are members of the same group occurs where intergroup inequality exists (Tajfel, 1979). Such inequalities jeopardise the self-esteem of marginalised group members, and lead to intergroup conflict and the development of an 'us' and 'them' scenario. Individuals align themselves with other marginalised group members in order to re-establish a sense of worth and affirm their compromised values and self-esteem. Here, Amanda aligns herself with permanent nursing home staff (us), and distances herself from care workers from outside the nursing home (them) (L251-256 above). Equally, where members of the out-group (agency staff) were considered by the in-group (participants) to hold the same care values as them, and to be competent to deliver care, agency staff were portrayed in a favourable light (Mary, L257-258 above). Previous findings suggest where there are high levels of occupational stress dignity conserving care may be resisted nurses and care staff as it is perceived as a further demand (Fulton, 1996). If such intergroup allegiance and occupational stress exists among staff as is demonstrated in the present theme,

arguably this has the potential for the development, spread, and maintenance of abusive care practice within an institution.

### ***Sub-Theme 2.2: Unheard***

Participants were also resentful of the undervaluing of older people's care and care workers in wider society. This was reflected in participants' use of upward social comparison between the resources and voice available to older people and care workers, and the resources received by prisoners and prison workers (L884-L889 below).

*P2 (laughing) they (prison workers) probably get better funding for activities than we do*

*P3 [they get National Vocational Qualification's and all sorts*

*P1 OF COURSE THEY DO because they're big enough and gobby enough to fight for their rights whereas these people (older people) who are really in need aren't big enough and gobby enough to fight for their rights (.) which is why we have to be big and gobby and fight for their rights for them (.) so*

*P4 yeah and we're their advocates*

*(L884-L889)*

Participants' talk demonstrated that in addition to feeling undervalued within society compared to others they deemed less deserving, participants also resented the fact that their voice was unheard. In the extracts below participants reflect how they felt let down not only by wider structural systems of whistleblowing, but also by the unprofessional breach of confidentiality by management at the personal level.

*P4 we've had a few incidences over the la (.) while I've been here for five years we've had a nurse that was (.) sacked as well (.) erm and I've had to give evidence against her and (1) yeah but now she works for an agency and you just hope one day that she never comes back to be (.) on agency.*

*(Lisa: L278-281)*

- P3 *before I've made statements against staff when I've been asked to from management (.) and without being told (.) the person in question has been shown the statements and (.) sort of like actually come to me and said oh (.) why (.) I didn't know (.) why have you written this about me bla di bla (.) [and (1)]*
- P4 *and confidentiality*
- P3 *very very awkward*
- P1 *it's shockingly unprofessional as well breaking every confidentiality rule in the book*
- P4 *yeah that's happened to me as well (.) confidentiality is isn't kept*
- P3 *very well*
- P4 *within the care setting yeah*
- P3 *it's quite demoralising sometimes isn't it a lot of stuff what happens but (1) just carry on and get on with it*
- Int *so does that make you (.) sort of more cautious about (.) saying anything the fact that*
- P3 *I probably wouldn't write a statement again about*
- Int *[yeah]*
- P3 *somebody if it was sort of getting them into trouble*
- P4 *it's very difficult isn't it*
- P3 *depends if it was a resident obviously if it was anything to do with a resident I'd always write something (.) but if it was like just staff*
- (L290-309)

Here, the previous nursing home manager had compromised attempts by participants to safeguard residents, which was in direct conflict with participant's self-identity as both a caring person, and professional care-giver (see theme 1). It also breached participants' desire and duty (obligation) to act as an advocate for residents, who participants positioned as being more marginalised than them (see theme 1). Participants, and Amanda and Lisa in particular, felt a loss of trust in Head Office and management due to the previous manager's breach of

confidentiality and the ineffectiveness of safeguarding protocols. Trust is considered to be central to the development of good relationships that are essential to the delivery of dignity conserving care (Brown, 2008), especially in long term care for older people (e.g., Nolan, 2006; McCormack, 2003). Considering the lack of understanding about the causes of abuse and why it is under-reported in nursing home care, such breaches of trust are of concern, especially as research suggests that not all carers have the courage to report the malpractice of co-workers (Heijenskjöld, 2010). Therefore, it is important that those who are courageous, such as Amanda and Lisa, feel safe to do so and have the confidence that their voice will be heard and acted upon to safeguard the interests of care-recipients.

### ***Sub-theme 2.3: Overworked***

In theme 1.2, participants distanced themselves from co-workers that had different care values and behaviour to theirs. In contrast, and despite experiencing the brunt of the nursing home manager's fatigue, participants showed empathy for her. They suggested this was because she shared the same care values as them, and also shared the same pressures from Head Office.

*P4    yeah perhaps (.) for instance] we don't have a deputy manager (.)  
they're seeing (name of manager) cope*

*P1    and so they're letting her*

*P4                                    so they're allowing her to*

*P1                                    have you seen how tired and ill and fraught she  
looks and have you noticed how snappy she is lately (.) and I love  
(name of manager) to bits I really do*

*P4                                    yeah it's not*

*P1                                    and I've got a lot of time and a lot of  
respect for her because I believe she shares my philosophies*

*P4                                    yeah I I think we all do actually*

- P3      *yeah everybody's got a lot of respect for her 'ant they*
- P4      *yeah*
- P1      *but I think I think that about 85% of the staff at the moment could cheerfully clog her*
- All     *heh heh heh*
- P1      *and yet we understand why she saying things the way she's saying them*
- P4      *but they put her in a compromising situation where she's controlled by head office and they're not giving her support (2)*
- P3      *no they're not*  
(L158-L175)
- P1      *... and eventually (.) people give up (.) and the ones who don't give up go on long-term sick with depression or whatever .... or leave the profession altogether (.) so erm (.) I can see how these shock horror things (.) start (.) you know where they come from...*  
(Mary: L127-L131)
- P1      *.....and then because of the pressure from head office (.) (manager's name) best advice at the moment is to delegate to my seniors (Senior Care Assistants) Amanda and Sally (.) but I see with my own eyes day in day out that they're working to their (.) beyond capacity some days (.) erm and I can't possibly countenance trying to shuffle some of my stuff that I haven't got time for sideways cos they've got enough on their plates*  
(Mary: L186-L190)

Participants' accounts and that of Mary in particular, indicate that the lack of support and recognition, and rationalised pressures from Head Office had a negative influence on the wellbeing of both the nursing home manager and care-giving staff. Participants' accounts were consistent with previous findings that a lack of autonomy is a predictor of burnout in care workers (Banaszak-Holl et.al., 1996). Participants' accounts ([L158-L175]; [Mary: L186-L190]), highlighted the conflict they experienced between their moral obligation to meet the rationalised demands of their employer, and their personal and professional obligation to adhere to their relationship-centred care values. Here, participants considered the values and beliefs of the nursing home owners to be disparate to their own,

which led to inner conflict and distress for participants. According to Tajfel, it is often impossible or very difficult for individuals to invest themselves in groups that are underprivileged, stigmatised, or unsatisfactory, which is how participants positioned their formal care-giver role.

Despite these challenges, the following discourse suggests participants had a strong sense of teamwork and allegiance to one another. They perceived this to be integral to their ability to deliver care and manage the psychosocial as well as the physical demands of care work.

*P3 yeah but really we're all together aren't we*

*P4 yeah but in order to*

*P3 we couldn't do it  
without each other could we*

*P4 yeah in order to  
look after someone fully (.) we need to work together to do that*

*(L35-L39)*

*P1 you know and if I want to keep the good rela working relationship I've got (.) which is the only way your gonna have a happy nursing home from the resident's point of view is if the staff are all happy and get on well with each other (.) I'm not placing un-necessary unfair pressure on Amanda and [says name of another Care Assistant] (.) I'm gonna try and continue to (.) do it (.) so I'm gonna continue to be criticised for doing too much or trying to do too much (.) you just can't win it's a vicious circle*

*(L190-L194)*

In accordance with Tajfel's integrative theory of intergroup conflict, such strong associations with others similar to us creates in-groups where the group members have similar interpersonal (individual) values, beliefs and behaviours to our own. In times of difficulty such intergroup associations strengthen and provide support to individual group members, and validate the individual's compromised self-identity. This may also enhance the self-esteem of group members. This cohesive strategy appeared to be adopted by participants to

maintain their morale and self-esteem during circumstances they portrayed as personally and professionally challenging. However, Mary perceived that there was a caveat associated with her hierarchical position. This dictated that in order to maintain this '*working relationship*', Mary must personally give more to protect the care workers she had a hierarchical responsibility for. This mirrored Mary's portrayal of the nursing home manager's tendency to do too much, which may suggest that in private sector nursing homes, senior workers such as Registered Nurses and managers are more susceptible to burnout than junior care workers such as Care Assistants.

**Summary of theme 2:** Participating nursing home care-givers highlighted their sense of feeling undervalued, unappreciated, and unheard by wider society and the nursing home institutional hierarchy. Participants harboured resentment due to a sense of injustice that stemmed from their perceived lack of material and moral support and recognition of their care-giver role. Participants' resentment was manifest in their expression of intergroup and intragroup tensions and low morale. Participants also attended to how this impaired their ability to deliver good care to residents. In contrast, participants' felt better able to care for residents through a sense of connectedness and allegiance to those who shared their own care values.

### Theme 3 – The Constrained Carer

There has been concern that the shift of long-term care for older people from the public sector to private sector may compromise the delivery care in practice due to the delivery of fewer lower quality services to maintain profit margins (e.g., Shadish, 1989). Indeed, there is evidence that services may not be provided more efficiently, despite the incentive of market competition from



other long-term care providers (Schlesinger et al., 1984). There is also debate that the National Health Service rationalised, medically driven, and individual centred approach to care is inappropriate for institutional care (Brown, 2008), especially long-term care for older people (e.g., Nolan, 2006). This is because it fails to consider the contextual and relational aspects of care required to meet older peoples' long-term care needs. Despite this my observations study (see study 1, Chapter 3) identified such rationalised and medical extra-discursive influences within the physical environment, and the policies and practices of participating nursing homes. In this theme I present the individual and contextual influences on staffs' ability to deliver their personal 'relationship-focused' philosophy of care in participating nursing homes.

### ***Sub-theme 3.1: Blame rhetoric***

When providing her account of what care meant to her the first thing Mary attended to in the focus group were the material extra discursive constraints she encountered in her formal role as care-giver, for instance, insufficient time.

*P1 well if it helps I came here from 30 years in the health service because I'm not allowed to care in the health service because there aint time (1) I hoped it would be a lot better here (.) it's better to some extent because its ongoing care over a long period of time (.) but I still don't have the time I would like to devote to my individual residents the quality time that they need and deserve and ought to expect as a right (.) but then I've been saying the same things for the last 30 years so (.) I don't expect things to change any time soon*

(Mary:L13-L18)

By citing barriers to care as external to her, Mary had positioned herself as blameless for any lapses of care that may be revealed during the focus group; such positioning was consistent across all participants' talk. Mary cynically attended to the longevity of material constraints (insufficient time) and how she had persistently highlighted this to no avail (L17-L18). Although she felt

constrained because her voice was unheard (also evident in theme 2), Mary still positioned herself as having a greater voice than residents and considered herself to be duty bound to act as their advocate. This supports the suggestion that the Health Professional is in a position of power over care-recipients due to their dependency upon Health Professionals to meet their care needs, especially in older peoples' care (Tronto, 1998). Participants' embodiment of the advocate role mirrors findings that nurses prioritise this role (Baille, 2009; Walsh et. al, 2002; Heijkenskjöld, 2010). However, this may impede the older persons' degree of autonomy, which they value highly as recipients of care (e.g., McIver, 2005).

### ***Sub-theme 3.2: Personal constraints***

All participants thought spending time with residents was an important aspect of care, which Mary considered to be a fundamental human right (L15-L17). Contrary to this positioning, Mary also intimated that care was conditional in that individual residents must both need and be deserving of care. How residents' right to care was ascertained was not explicit, although Mary later said that she gave equally to all residents when at work (professional self), but gave more to those with whom she has a personal connection when off duty (personal self) (Mary: L989-994).

*P1 but y' know just as (1) y' know we try to do our best for all twenty one of 'em (.) if we care at all then we're going to care more deeply about some than others because (.) they are more complimentary personalities than others so just as you choose your friends or people you become friendly with (.) doesn't mean to say that just because I'm (.) for example I'm great friends with Laura doesn't mean to say that for one second I would give her a better standard of care (.) or more of my time when I'm here in my uniform (.) than I give to say (1) Betty who's harder to reach*

(L989-L994)

Consequently, for Mary, caring “*more deeply*” about residents was dependent upon factors beyond yet interwoven with her rationalised personal values, beliefs and professional care-giver status; engagement in caring deeply required personal and innate dispositional compatibility, and was therefore emotionally laden. Thus, Mary was constrained from delivering care equally to all residents by her own feelings, which conflicted with her socially constructed philosophy of care to give equally. This resonates with Cromby (2007) who suggests that our feelings remain dormant and are ignited by material and cognitive influences. In an attempt to redress this imbalance, when in her professional care-giver role, Mary suppressed her differing feelings for individual residents and divided her limited time equally among them in order to maintain her professional care-giver identity. By giving more to residents that she cared for deeply when off duty she was better able to fulfil the emotional demands of her personal care-giver identity.

### ***Sub-theme 3.3: Role-related constraints***

In addition to dispositional constraints and the material constraint of insufficient time, focus group participants also identified other barriers to their ability to care well. Consistent with previous findings (e.g., Dunn, 2014; Harmer, 2008) these included a medically driven and rationalised approach to care, and insufficient staff, equipment, physical space, staff training, and transport for residents. The constraints referred to in participants’ talk reflected the extra-discursive influences that previously identified in my observation study and literature review (see Chapter 3). Participants each cited extra-discursive influences that specifically affected their formal care-giver role.

For instance, Josie and Mary in particular felt frustrated by the medically oriented nature of their formal Registered Nurse job role and the hierarchical restrictions on engaging with residents at the psychosocial level, which they considered integral to care. Medical and routine practice was more poignant during the day and had influenced Josie to continue working night shifts in order to achieve her care ideology and maintain a sense of fulfilment and integrity in her formal care-giver role.

*P1 and I don't know if Josie finds it any better on nights (.) but I've been told by two separate managers I shouldn't be talking to mi residents while I'm giving them medicines I need to be in there and out of there so I can prioritise getting through the drug round as fast as possible (.) and I don't know if I agree with that ... (L45-L48)*

*P2 why I prefer to stay on nights is because (.) there is like in the morning like Mary says there's a rush (.) with medications because (.) there's some more medications to give at lunch time and there's the rest of the day to get on with whereas in the evening there's no rush to get them done (.) or to get everything (.) done quick because you've got the whole night to catch yourself back up....(L69-L72).... what I do like about nights (.) is that there is (.) you you never go home in the morning with the feeling (.) that you didn't do everything that you could for everyone (.) that there wasn't time to do everything everyone wanted or needed (.) because there is*

*P3 it's not like that on days*

*P2 whereas when I worked days as a nurse in a nursing home that was really busy (.) you know when people who were lonely residents who wanted to talk and things and you just didn't have time to (.) stop in their room and talk to them or anything like that and you were straight (.) and and you would (.) all the time for short staffing and things you went home in the evening feeling terrible.*

*(L69-L83)*

Despite sharing the same Registered Nurse role, there was a distinct contrast between the care-giver experiences that was determined by the time of day when care was delivered, which echoes previous findings (Kerr, 2008). Institutional medically driven routine working practices and the high demands of physical care associated with daytime working were portrayed by participants as

restricting their engagement with the psychosocial aspects of care. Both Registered Nurses perceived this as having a negative influence on their own wellbeing, although Josie purposefully distanced herself from the pressures of such medically-driven time-constrained working practices by working at night.

Lisa identified different frustrations in her role as Activities Coordinator and found it “*very painful*” (L1024) that she was prevented from organising social events for residents using volunteers as there were limited resources to do so within the nursing home. This conflicted with Lisa’s holistic ethic of care. Lisa was left to manage the burden of residents’ disappointment despite the fact that restrictions on social engagement with residents were imposed by the nursing home hierarchy.

*P4 I’ve been constrained because actually (.)*

*P1 she’s not even allowed to spend  
the time*

*P3 planning somebody else to do it (.) a volunteer*

*P1 planning potential events that would depend on the good will of staff*

*P4 yeah*

*P1 which I find appalling*

*P4 that’s a whole other kettle of fish isn’t it because what I believe as a  
standard of care (.) is restricted to what I’m allowed to do*

*P1 yep*

*P4 because I’m at the bottom of the hierarchy of management*

*P3 but you get it in the neck not them (.) I think that’s what*

*P4 and so I’m the person on the floor with the residents who (.) it’s very  
painful to tell someone (.) I can’t (.) I would live by the seaside when  
I’m older (.) so to tell someone I can’t take them on one trip to the  
seaside (.) is very (.) and see how upset and angry that makes them  
(.) and affects their mood for the rest of the few months is very  
difficult (1) and and I go home and have to reconcile (.) like what I  
believe with what I get told I can do and it’s very difficult*

(L1012-L1028)

Here, Lisa's account reveals that her self-identity as a caring person and her personal ethic of care was compromised by material and structural constraints. Her frustration was acknowledged and shared by all participants. Where person-related and job-related variables are considerably misaligned (Cohen et al., 2009) and work stress is negatively perceived (Lazarus, 1980; 1985) the likelihood of care workers experiencing occupational stress is increased, and vice versa. Mary's and Lisa's accounts were more aligned with the former and Josie's with the latter, which suggests occupational stress was perceived as greater for participants working during the day compared to those working at night, regardless of job role.

#### ***Sub-theme 3.4: Generic constraints***

All participants considered knowledge and skills to be central to their ability to deliver good care. For Amanda in particular, insufficient training was a constraint on her ability to care for others, and meet her own needs, for example, when residents died. Amanda's perceived lack of knowledge and skills compromised her ability to deliver emotional and psychosocial support to residents and their relatives, particularly at the end of life. This is of concern as residents at the end of life are particularly vulnerable to loss of dignity due to their increasing dependence and loss of control over their bodies (Franklin, 2006).

*P3 and it's quite awkward with the families I feel sometimes you just sort of don't know what to say (.) or how to be I've not like (.) had any training in bereavement or anything so (.)*

*P4 bereavement counselling really*

*P3 yeah (.) just like a little training session would be good but*

*P4 oh I'll have to show you some stuff*

(L686-L690)

Amanda's talk revealed the opportunity for her to engage with the psychosocial care needs of all parties involved in end-of-life care was constrained not only by the necessity to balance her own needs with those of residents (as outlined in Theme 2), but also by a lack of knowledge. In general participants said that some training they received was useful, although most was too generic and not bespoke to the needs of participants' specific job role or to the nursing home environment, which supports findings by Sheffield LINK (2011). This deficit exists despite research suggesting more psychosocial training is required for Health Professionals (Maben, et. al., 2010). All participants placed knowledge and skills as a facilitator to good care practice and attended to their knowledge and credentials when constructing themselves as good carers throughout the focus group, which was evident in the extract below.

*P1 but I've been criticised by that and patted on the head and told carer's don't need to know in that depth (.) to which I'm sorry (.) carers need to know the answers to as far as their as their questions take them(.) y' know*

*P4 and also (.) by saying the carers don't need to know that*

*P1 how patronising (.) how arrogant*

*P4 you're not giving them the chance to learn (.) and you're not giving them a chance to be trained up*

*P3 yeah (.) I love working with Mary (.) I always ask questions*

*P4 and give them confidence to*

*P1 who's doing eighty five percent at least of the hands-on [care*

*P3 yeah so if we know for next time what to look for*

*(L724-L735)*

Here Mary and Lisa, who were hierarchically senior to Amanda as Care Assistant, positioned themselves as being more knowledgeable (L724-L729). In keeping with their self-positioning as 'giving' individuals, they were willing to share

their wisdom with those less knowledgeable, such as Amanda. Amanda attended to her lack of knowledge as being a barrier to delivering care, and positioned herself as being receptive to learning (L731). Amanda appreciated her ability to learn was acknowledged, advocated and nurtured by her senior colleagues, which appeared to bolster her self-esteem. Mary was particularly frustrated about being patronised (“patted on the head”) and constrained by Head Office from giving training to Care Assistants when on duty. To Mary this represented a lack of recognition of her knowledge (professional care-giver) and a rejection of her desire to give (vocational care-giver), which were integral to her ‘vocessional’ self-identity. Although participants’ views mirror findings that shared learning and ethical leadership facilitate partnership, increase staff enthusiasm, and promote a sense of being valued (Gallagher, 2017), these views were suppressed at organisational level.

Additionally, participants’ focus on knowledge corresponded with Foucault’s (1982) idea that knowledge is power. Here Registered Nurses and Activities Coordinators positioned themselves as more knowledgeable and as in a position of power over Care Assistants within the nursing home. All participants attended to the fact that Care Assistants had least knowledge, and congruent with previous findings (e.g., Banaszak-Hol, 1996; Felton, 1998; DOH, 2009b), suggest this reduced Care Assistant’s ability (power) to deliver good care to residents. This is of concern as participants also positioned Care Assistants as being best placed to deliver care to residents due to the hands-on nature of the Care Assistant role. Participants positioned Head Office as lacking the knowledge and experience to understand the nature of ‘care-giving’ in practice, and as responsible for constraining participants’ opportunity to improve the care they delivered to residents through the accumulation and sharing of knowledge. This is of concern



as knowledge and skills in organisations and among formal carers is required for a positive social environment to exist for people experiencing dementia (Bradford Dementia Group, 2004). Yet participants' commitment to improve their knowledge in order to deliver good care was not unconditional. Despite positioning knowledge as central to her ability to give good care, Amanda placed boundaries on what she is prepared to give freely (L694-L695).

P3 *training I went on last month I didn't even get paid for so I won't be going on any of that again*

(L694-L695)

Once again participants experienced a tension between balancing their own needs with the desire to accumulate knowledge. This may reflect the resentment participants harboured towards Head Office due to feeling unappreciated, unheard and overworked (see Theme 2). Additionally, participants considered that the 'for-profit' nature of the organisation compromised the delivery of holistic care to residents.

P3 well whichever one it is (.) they've (HO) paid for this tree and we've got no equipment (.) we've got baths that don't work (.) and

P1 *yeah both our  
Parker baths have been condemned for how many years now?*

*P3 two years*

P4 yeah we seem to have enough money to pay for a plant that cost about three hundred quid a year that would pay for a bed wouldn't it I suppose

(L561-L567)

P4 *that fish tank should be on red floor for the residents to look at*

P1 *it's all about image and not substance if they're (HO) gonna pay for a flaming fish tank it ought to be*

P4                      put it on the floor

P1 *exactly it should be where the residents can benefit from it*

(L579-L584)

It is evident that participants were vexed about Head Office's lack of investment in material resources to deliver both the physical (L561-L567) and psychosocial aspects (L579-L584) of care to residents. This was exacerbated where participants felt that the management had prioritised the public image of the business over the care needs of current residents in order to attract more custom. This rationalised 'for profit' model conflicted with participants' care ethic, and is refuted for the delivery of quality care (e.g., Brown, 2008).

**Summary of theme 3:** Participants accounts highlighted how extra-discursive influences such as: a culture of blame; time constraints; a medically driven rationalised model of care; failure to meet staffs' training needs; and staff feeling undervalued by management, restricted nursing home staffs' ability to deliver their personal 'relationship-focussed' philosophy of care. In addition to contextual influences on their ability to 'care', nursing home staff also experienced a tension between their desire to deliver care equally to all residents, and embodied (feelings) dispositional constraints.

### Summary of Findings of Staff Focus Group Study

The findings of this focus group study add to existing knowledge in that they provide an insight into care-giving from staffs' perspectives regarding the meaning of 'care' specifically in nursing homes, whilst uniquely considering contextual influences on staffs' ability to deliver their 'care' ideology in practice. I found that staff self-regulated to wider discourses of 'power' and felt 'obligated' to adhere to their 'professional' carer identity, which left them feeling disempowered by the nursing home hierarchy yet empowered over residents. There was a tension for nursing home staff who felt resentful and constrained by rationalised and risk-adverse discourses that were external to them. They felt

constrained and only able to deliver their 'vocational' relationship-centred care ideology to residents with whom they felt a personal connection, and in their own time. These findings are triangulated with the findings of the observation study (Chapter 3) and the resident interviews study (Chapter 4), and discussed collectively in the thesis 'overall discussion' (Chapter 6).

## **Chapter 5: Study 3 – Interviews with Nursing Home Residents**

### **Introduction**

Being a resident in nursing homes for older people in the United Kingdom is a unique and little understood experience. It is one that is important to comprehend due to the increasing ageing population and protracted need to provide appropriate care. In order to do so we need to gain insight into the day-to-day experience of older residents living in nursing homes. We need to ask residents what care means to them and what they expect from the care they receive. Are there any discrepancies between what residents and nursing home carers consider 'care' to be, and how does this impact on the delivery of appropriate care? The aim of answering these questions is to better inform stakeholders including care commissioners, care regulators, care providers, and care givers about how to shape and deliver appropriate nursing home care both now and in the future. Therefore, this chapter presents the third and final study of this doctoral research that, through the use of visual methods and Thematic Analysis, provides nursing home residents' perspectives of what care means to them. Findings are discussed in chapter 6 along with findings from study 1 (ethnographic observations) and study 2 (nursing home staff focus group) drawing on existing literature to determine embodied and contextual influences on care in participating nursing homes.

## Method

### ***Participants***

A purposive sample of volunteer residents was recruited across three participating private sector nursing homes for older people (see procedure). In total seventeen volunteers were recruited, fourteen women and three men age between 74 years and 100 years, all were White British. Of these, one woman in nursing home 2 and one man in nursing home 3 were unable to participate in the interview due to ill health. A second woman in nursing home 2 was withdrawn from the study by her relatives within seven days after being interviewed as they felt she was not able to give full consent.

In total fourteen interviews were included in the analysis: twelve with women and two with men (see 'Table 5: Demographic information' below). In addition, the wife of a resident who had debilitating dementia volunteered and was interviewed on her husband's (pseudonym Larry) behalf to tell his story of entering nursing home care. This interview transcript was not used in the present analysis as it was not a direct account of Larry's perceptions of 'care' and nursing home life. Of the fourteen residents interviewed, one man and one woman opted to take photographs themselves in addition to the photographs taken by me for all residents on their behalf. The main reason for opting out of taking photographs was resident's inability to mobilise independently around the nursing home e.g., due to experiencing a physical or cognitive condition such as arthritis/stroke or dementia.

**Table 5: Demographic information for residents that participated in photo elicitation interviews across each of the three participating NHs**

NH (NH)	Pseudonym	Who Took Photographs	Sex	Age	Weeks in NH	Ethnicity
NH1 R1	Fred	Both*	M	87	24	White British
NH1 R2	Harry	Researcher	M	95	30	White British
NH1 R3	Jessy	Researcher	F	93	78	White British
NH1 R4	Betty	Both*	F	85	10	White British
NH1 R5	Molly	Researcher	F	90	25	White British
NH1 R6	Doris	Researcher	F	100	13	White British
NH2 R1	Pat	Researcher	F	90	84	White British
NH2 R4	Mary	Researcher	F	85	72	White British
NH3 R2	Hilda	Researcher	F	88	26	White British
NH3 R3	Annie	Researcher	F	83	12	White British
NH3 R4	Kath	Researcher	F	92	50	White British
NH3 R5	Shirley	Researcher	F	74	3	White British
NH3 R6	Vera	Researcher	F	80	18	White British
NH3 R7	Nancy	Researcher	F	83	18	White British
NH = NH      R = Resident      Both* = Researcher and Resident						

### ***Procedure***

Ethics Approvals - I applied for and obtained ethical approval for all three studies conducted in participating nursing homes from Sheffield Hallam University (Sheffield Hallam University) (appendix 0.1 and 0.2) and the Local Authority (appendix 0.3) ethics committees in accordance with the British Psychological Society (BPS, 2009) ethical code of conduct. I also obtained full Disclosure Barring Service (DBS) (formerly Criminal Records Bureau - CRB) clearance for research with vulnerable adults (appendix 0.4).

Recruitment of volunteers involved placing advertising posters on notice boards (appendix 2.1), holding a brief presentation in each nursing home about the overall PhD research, and providing each resident with a study-specific information sheet (appendix 3.1) and a volunteer reply slip (appendix 3.2). Volunteers were each offered a £10 high street voucher funded by Sheffield Hallam University as further incentive to participate. Reply slips were placed in a sealed box in reception for later collection by me (the researcher). I contacted volunteers in person or by phone, and arranged to visit them in the nursing home a fortnight before taking part in interviews at a mutually convenient time. Lasting Power of Attorney (LPA) applied for one resident (pseudonym Annie) therefore her advocate (son) was also present. I introduced myself and explained: the purpose of the research and read through the participant information sheet (appendix 3.1). I explained that taking part would not impact on the care they receive in the nursing home in any way; that there was no obligation to take part; the resident's right to withdraw up to 7 days after the interview; and how anonymity and confidentiality would only be breached by the researcher if safeguarding issues arose during the interview. For safeguarding purposes residents were also asked to complete a form stating who they would like me to contact in support should they become distressed during interviews (appendix 3.3). Residents, (and in Annie's case her son) then signed the consent form (appendix 3.4).

If the resident had opted to take photographs themselves, I also gave them a numbered disposable camera and instructions on how to use it. The camera was collected by me a week later to be developed. Photographs that were taken by residents included photographs in the grounds of the nursing home and both inside and outside of the residents' own room. All photographs I took were of the

residents' personal living space (bedroom) on the resident's behalf. These photographs captured a 360 degree panorama view of the inside of residents' own bedroom, their en-suite toilet and views from the bedroom window to ensure consistency across interviews and nursing homes (see table 6 for example photographs). The rationale for photographing residents' own room is that during observations conducted in study 1 (Chapter 3) residents spent approximately 70% of their time there. Also, each resident's room represented their unique experience of nursing home living in addition to the communal experience previously observed. Where residents were not taking the photographs, I encouraged them to offer suggestions about what they would like me to photograph. One resident asked me to take a photograph of the view from her window as she was chair-bound and unable to see it (Nursing Home 2 Resident1-Pat [NH1 R5-Pat]) and another because she liked the window-view she had (NH1 R5-Molly). No residents suggested taking photographs of the nursing home beyond their bedroom. In all 14 interviews a total of 365 photographs were taken with an average of 26 photographs per interview. Approximately two weeks after obtaining the resident's consent to participate in interviews I took the developed interview photographs to the nursing home and repeated the consent process to confirm that the resident still wanted to take part in the interview.



Table 6: Examples of Photographs taken in the bedroom of participating residents in each of the three participating NHs

Name, Image & Photo Ref	Photograph	Name, Image & Photo Ref	Photograph	Name Image & Photo Ref	Photograph
<b>Fred</b> NH1 R1  TV and Storage		<b>Doris</b> NH1 R6  View from Bed		<b>Kath</b> NH3 R4  Bedroom toilet	
<b>Harry</b> NH1 R2  TV Guide		<b>Pat</b> NH2 R1  View from Chair		<b>Shirley</b> NH3 R5  Call buzzer	
<b>Jessy</b> NH1 R3  Grandma figure		<b>Mary</b> NH2 R4  Bedroom sink		<b>Vera</b> NH3 R6  Bedside table	
<b>Betty</b> NH1 R4  Oxygen machine		<b>Hilda</b> NH3 R2  Anniversary Plate		<b>Nancy</b> NH3 R7  Wheelchair	
<b>Molly</b> NH1 R5  Sunny Window		<b>Annie</b> NH3  Food stash			

Unstructured audio recorded interviews were carried out in resident's bedrooms, with the conversation being started by introducing myself and the purpose of the research, and then asking residents to share their experience of what care represented to them, and their experience of the care they received in the nursing home. Photographs were introduced as a talking point when residents themselves referred to them of their own accord, or by me to stimulate further talk on the topic of interest: for example, residents were asked to talk a little about the content of the photographs and what if anything they represented for them.

Immediately after the interview I went through each photograph with the resident to obtain their written consent to use photographs in the present research, and for future dissemination of research findings. The consent form included the option to include or exclude a photograph in its entirety (appendix 3.5), or to blur out any identifying information on individual photographs, such as faces (appendix 3.6). The photograph consent form was designed so that only one signature was required for multiple photographs as many residents experienced difficulty writing due to a physical impairment. On conclusion of interviews, I provided residents with a debrief sheet to keep (appendix 3.7), explained again the aim of the research and the resident's participation, and gave them the opportunity to ask any questions. I did not leave the resident until I was happy that they were comfortable and able to call for assistance using the nurse call buzzer.

### ***Photo-elicitation***

Photo-elicitation is defined as using a photograph in an interview, and for the purpose of this study this is appropriate because it enables the researcher to explore the individual's self in relation to society, culture and history (Harper,

2002). During interviews, residents used these photographs as discursive anchors in their accounts of their lives prior to and since moving into the nursing home. Table 6 provides an example photograph from each of the fourteen interviews showing a range of content that is representative of the photographic images captured: for example, personal objects, photographs, and furniture and equipment. Some residents were happy to be photographed and have their image used in the thesis, and for wider dissemination purposes.

### ***Transcription and Coding***

Resident interviews were transcribed using orthographic transcription (see appendix 2.10) symbols that were retained within extracts for the present study. Data analysis started during the interview audio data transcription phase, and continued during my systematic and rigorous reading and re-reading of the transcribed data corpus (see example of annotated transcription in appendix 3.8). As outlined in detail in Chapter 2: Overall Methodology I followed Braun and Clarke's (2006) guidance and conducted an inductive, semantic and latent thematic analysis on present study data that was further influenced by Critical Thematic Analysis (Lawless, 2019). This included rigorous and systematic filtering for codes and subsequent themes within the data to the point of data saturation. During thematic analysis, I colour coded resident interview transcriptions in order to distinguish the occurrence and prevalence of particular discourses for each participating resident.

In the second 'coding' phase I generated codes that comprised of words, sentences or subject content. Coded data was then grouped into themes and sub-themes that were representative of the individual and group depictions of the topic of interest by all participants. Each theme and sub-theme are presented in

Table 7. To facilitate this process data was organised in an excel spreadsheet (for an example see appendix 3.9). I retained the origin of each coded/themed data extract by preceding it with a speaker identifier. For example, the resident speaker ID 'Fred NH1R1' comprises of a speaker pseudonym (Fred) followed by the nursing home number (NH1) and participant number (R1) for each resident, followed by the transcript line number in which it appeared (e.g., L24-25). All resident participant numbers and pseudonyms are outlined in Table 5. The identifier 'INT' was used for all interviewer dialogue.

### ***Study-specific Analytical Process***

Photographs used in research, such as the present study, are given meaning by words so it is important that participants are allowed to interpret photographs, and researchers analyse them, using the words of research participants (Stanczak, 2009). These narratives can help to make sense of experiences and to construct social identities (Somers, 1994) with authors such as Bruner (1990) suggesting that they help the individual to convey to others their experience and knowledge. In doing so it opens up the potential for participants to reveal the embodied experience of complex concepts such as health, illness, and care, while taking into consideration the social context in which they are experienced and shared

Within psychology Keneth Gergen and Mary Gergen (1986), suggested that narrative accounts of experience are guided by three discourses: first *progressive* that enhance the storyteller's movement towards a particular goal; second *regressive* that impedes progress; and third *stability* where no change occurs. Simultaneously, Doise (1986) proposed four different levels for consideration

within narrative analysis that are summarised by Michael Murray (2000) and Christina Stephens (2011) and considered applicable for research within Health Psychology. First, the psychological or ‘intrapersonal’ level, which represents how the individual interprets the world; second, the ‘interpersonal’ level, which reflects the interaction between individuals involved in the situation; third, the ‘positional’ level which considers the social positions of actors involved in the situation; and fourth, the ‘ideological’ level, which takes account of wider belief systems (Murray, 2000; and Stephens, 2011).

Murray (2000) highlighted that narratives constantly overlap between these four levels of analysis, and therefore integrating the ontologically conflicting theories and variable approaches used by researchers during analysis at each level is difficult. Within Health Psychology Christina Stephens (2011) successfully adopted a critical realist approach to narrative analysis, which bridged this ontological divide and successfully explored the ideology of positive ageing and the influence of wider social context on women’s constructions of growing old and retirement. Stephens and Breheny (2013) also successfully integrated Murray’s four levels to avoid their artificial separation when interpreting stories by merging the positional and ideological aspects into one level named *the public narrative* (shared narratives of social life including moral and social identities). The remaining two levels were referred to as: *the personal story* (depicts the individual’s story of their own experience); and *the interpersonal* (the jointly constructed story that emerges through interaction between the narrator and listener).

Therefore, considering that the present Critical Realist research aims to elicit older nursing home residents’ embodied accounts of care within the nursing

home context, I felt it appropriate to draw upon narrative analysis guided by Murray (2000), and Stephens (2011), and utilise three levels of narrative (in accordance with Stephens et al., 2013) in the Thematic Analysis of the present study data. My reflection as researcher on the use photo-elicitation and the principles of narrative analysis in the present study is presented in appendix 3.10.

### Analysis: Presentation of Findings

In this section I present my findings from Thematic Analysis of interviews with fourteen older residents living in participating nursing homes. Residents' perspectives are presented in three themes (see table 7), each with sub-themes that represented participants' positions regarding 'care' in consideration of discourses at wider contextual, organisational and also individual (relational) level. Theme 1, 'Constructions of Care' outlines residents' personal care ideology that is aligned with a relationship-centred ethic. Theme 2 'Journey into the Nursing Home Community' provides insight into how and why participants came to reside in the nursing home and their positioning of this as beyond their control. Finally, Theme 3 'Adjusting to Nursing Home Living' demonstrates the constraints and enablers residents had experienced during the process of rebuilding their self-identity and establishing an 'acceptable' role within the already established nursing home community.

**Table 7: Themes and sub-themes from interviews with nursing home residents**

Theme and Title	Sub-theme	Sub-theme categories
Theme 1 Constructions of 'Care'	1.1 Care Context	a) Care Relationships
		b) Care Types
	1.2 Care Obligations and Contradictions	a) Unconditional caring about/for others
		b) Conditional care-giving by/for residents
	1.3 Care Currency: 2 way transaction	a) Expectations of care
		b) Payment in kind
Theme 2 Journey into the Nursing Home Community	2.1 Blame and the ageing body	a) Reasons for entering nursing home care
		b) Perceived burden
		c) Blame: loss, aging and illness
	2.2 Justification for care receiving	a) Moral high ground
		b) Stoic or be damned
Theme 3 Adjusting to Nursing Home Living	3.1 Characteristics	a) Control
		b) Accepting, belonging, duration
	3.2 Transforming self-identity	a) Finding a niche
		b) Resources: Scarce or otherwise

## Theme 1: Constructions of 'Care'

In Theme 1, extracts from residents' talk are presented, but due to the subtle differences in resident's individual accounts of care, the extracts are examples that best reflect residents' collective discourse about care, and also any strong contradictions to the views of the majority.

### ***Sub-theme 1.1: Care Context***

#### *1.1a) Care Relationships*

In their talk all residents consistently constructed their sense of what care represented to them by drawing on wider public ideologies that constructed care as being between two or more people and also between people and their pets: thus, for all residents, care exists in the context of a relationship. This is consistent with the relationship focused theories and models of care outlined in chapter 1 that are considered appropriate for long term institutional care of older people. The care relationships referred by residents living in each of the three participating nursing homes included family units, pets, friends, and community groups.

In the following examples, residents reflect on care relationships they experienced before living in the nursing home. Here Molly speaks fondly of her late husband, Annie of her large family, Harry of his former pets (see Photograph 3), and Doris of a close friendship:

#### **Extract 1 - 4**

**Molly NURSING HOME1 R5 L212** oh we always had a happy life (.) although there was just the two of us y' see



**Annie NURSING HOME3 R3 L43-L44** aye (.) I used (.) yeah (.) I knew what it were like having a family (1) we had a big family y' see (.) we had a biggish family

**Harry NURSING HOME1 R2 L68-L75** oh about ten years ago I had animals I loved 'em (.) but they were all the same (.) they were all border collies and they're very intelligent y'know ... I think they're more intelligent that we are heh heh heh heh

**Doris NURSING HOME1 R6 L195-203** ... and that's (friend's name) I worked at the (organisation name) with her (.) and er she lived at em (1) (town name) (.) well we used to I used to go there for one holiday an' she'd come to me .....I miss her very much yeah (friend's name)

**Photograph 3 – Harry's loves animals and has photos of dogs and cats in his room along with a cuddly dog to keep him to keep him company**



Only Doris described maintaining a relationship with groups in the wider community. This was only possible because members of her former parish congregation demonstrated they cared by carrying out practical acts of care-giving, such as collecting her from the nursing home to join group activities in person. Such care acts are integral to Tronto's Ethic of Care (1998), and also Nolan's (2004) senses of 'Continuity', 'Purpose', and 'Significance', which are integral to promoting self-worth.

#### **Extract 5**

**Doris NURSING HOME1 R6 L26-L29** that's the three friends (.) and besides the friends at the erm (.) chapel (.) they're very kind all of them particularly (.) (**minister's name**) the minister she's er (.) an' er (**organist's name**) the he's the (.) organist and he's he fetches me every Sunday morning (.) and every Tuesday to go to the luncheon club (.) so they're all very kind

Most described having developed relationships with other residents within in the nursing home, although their talk suggested this was usually at a superficial level, perhaps going down to lunch, activities, or the lounge to mix with others for a while, but then going back to their own room to have some personal space.

#### **Extract 6**

**Pat NURSING HOME2 R1 L735-L741**

**INT** do you have lunch in your room or do you go? (**to dining room**)

**Pat** yeah (.) no I should go (.) it's a sore point (.) I won't go (.) I don't like some of the people (.) I'm not a snob by any means (.) but I don't like some of the people..I can hear sometimes some of the (.) talk (.) "stuck u so 'n' so I don't like her" y' know you can hear all this sort of thing (.) and I want to say (.) I would have said it once but er (.) I want to say "what the hell's it got to do with you?" heh heh (.) that's what I feel like saying

Here Mary and Fred recalled conversations they had each had with residents that experience dementia. Mary experienced a physical incapacity due to a stroke, but considered experiencing dementia as being 'terrible', and

positions residents as blameless for any 'obnoxious' behaviour they may display. Similarly, Fred was tolerant of the repetition he encountered during conversations and normalised it within the context of old age. This mirrors findings where older people were found to narratively disassociate themselves from blame for illness (Murray, 1997: and Jolanki, 2004). Present findings suggest that where blame for challenging behaviour was deemed to be external, residents showed empathy and were willing to interact with other residents despite the challenges this entailed. This may be due residents needing to form meaningful relationships to feel part of their community, and have a sense of 'Belonging' (Nolan, 2004).

### **Extract 7 – 8**

**Mary NURSING HOME2 R4 L588-L593** "nobody wants me" (.) I said "oh of course they do" (.) "I wish I were dead" (.) I said "oh that's silly talking like that" (.) "nobody wants me" I said "course they do (1) they want yer in here" (.) but you do get that and (**other resident's name**) is brilliant (1) she doesn't know what she's doing she used to be a (job role) in hospital (.) and she's very confused she walks all oer t'place (.) some days she's great and other days (.) she's obnoxious you can't do nothin' wi her (.) but she doesn't know she's doing it bless her (.) terrible y' know init?

**Fred NURSING HOME1 R1 L8-L74** I get on wi most people here kind o' thing, but they're old people aren't they. Y'know like fo' mi meal I sit at side of a fella, he's ninety odd year old, ninety-five is he? You don't get no sense at all out of him heh heh

One resident in particular (Hilda – extract 9) demonstrated her capacity to quickly develop meaningful relationships with other residents. Throughout her interview Hilda talked of her gregarious nature, which may have facilitated this. Despite this, Hilda also demonstrated awareness of her need to balance the emotional investment required by her to continue her newfound relationship, against the sense of loss she may experience due to the inevitable and imminent death she anticipates will soon befall her new friend at her great age of 100yrs.

## Extract 9

**Hilda NURSING HOME3 R2 L158- L183** there were a lady she were a hundred an' odd (1) she came in for four days (.) not long ago.....an' er she were really lovely (3) yes she sent me this bunch of flowers (1) an' well they've gone now (.) yeah but she sent me that card (9.) from home

**INT** oh (.) right (.) and why do you think she did that?

**Hilda** but I don't I don't know where she lives (.) or no address

**INT** right (.) do you think you'd like to contact her?

**Hilda** I would 've liked (.) but er (.) she's hundred and odd (.) an' (.) I thought (.) well (3) y' know (3)

**INT** what (.) you thought well I know what? (4)

**Hilda** well I thought I thought well (2) she's getting on in years (.) 'n' she'll not be here much longer (.) ha hah hah hah (.) y' know

**INT** yeah

**Hilda** but I shall never forget her

This caution in relationships between residents is consistent with Tronto's 'Ethic of Care' (1993;1998), whereby care givers consider their own needs when investing in their relationship with care recipients. This sub-theme shows that residents reminisce with affection about relationships they had lost prior to or since living in the nursing home. Most seemed willing to try to develop new relationships with other nursing home residents, but found this challenging: partly due to incompatible disposition or capacity (either physical or mental), and partly due to the need to protect themselves emotionally when relationships with other residents end due to the imminent certainty of death.

### *1.1b) Care Types: Caring about, Care-giving and Care-receiving*

Consistent with Tronto's Ethic of Care (1993; 1998) residents perceived care as three distinct things, first 'caring about' others, which is the feeling of caring for someone and is demonstrated through emotional work; second 'care-giving', which is the demonstration of caring through giving practical assistance

with physical or emotional needs; and third 'care-receiving', which mainly refers to being supported with physical or emotional needs.

### *Caring about*

When describing how they 'cared about' others residents usually used 'felt' emotions that were often talked about in relation to a sense of loss of another: either through bereavement or through no longer being in contact with the person that the resident had feelings for. During present interviews, and consistent with previous theory (Goffman, 1971), photographs and objects held sentimental value for residents and served as an anchor to the past. For example, they stimulated residents' talk of caring about someone they had lost before coming to live in the nursing home. In Hilda's interview the object was a photograph of her grandson (extract 1), and for Kath an ornament was the focus of her reminiscence (extract 2, and photograph 4).

### **Extract 1**

**Hilda** NURSING HOME3 R2 L426-L432 y' know photographs (.) there's not many (.) but er (1) he put that one up (.) an' put er (1) (**grandson's name**) an er (.) the one that got killed

**INT** yeah (.) your grand son

**Hilda** an' I wave to him every day (.) as though he's here (2) oh I did love him (1) he used to follow me all over (2) and I used to buy him all his little (.) jackets

**INT** yeah

**Hilda** aye it broke my heart when he went (5)

### **Extract 2**

**Kath** NURSING HOME3 R4 L309-L314

**INT** yeah (4) what about this ornament can you see that one that's on your window ledge

**Kath** I know what you're gonna tell me (.) black cat

**INT** yeah (.) is there a

**Kath** .. I didn't you know bring a lot of things (.) I brought mi glasswear but er (2) I said I'd never part wi this it were mi brothers (1) gone he's dead now

**Photograph 4 – Image of object in Kath's bedroom brings back memories**



In addition to bereavement experienced prior to nursing home life, residents also appreciated the opportunity to grieve and show their final respects to residents they cared about and their family, which on this occasion was available within the nursing home (extract 3). Such provision by the nursing home complies with the Person-centred Nursing Framework (McCormack, 2010), specifically around having a sympathetic presence, working with resident's beliefs and values, and providing supportive organisational systems.

### Extract 3

**Mary NURSING HOME2 R4 L560-L581** mi grandson him there (**referring to photograph on her wall**) always brings me one (.) he used to bring one for (**deceased resident's name**) (.) but (**deceased resident's name**) died last week funeral's o' Friday (.) so he used to bring one for me and one for her and she used to love it (.) a dripping cake

**INT** was (**deceased resident's name**) one of the residents?

**Mary** yeah (.) she died last week (.) they bury her on Friday

**INT** was she a friend of yours?

**Mary** she were lovely old (**deceased resident's name**) yeah (.) and whenever I took her owt it were always (.) "how much?" I said "we don't talk about money in here y'know"

**INT** yeah

**Mary** yeah she were nice (.) they're coming back here after t' funeral (.) (**deceased daughter's name**) her daughter has been up to me and said "will you come down for a cup of tea Mary when we come back?" (.) I said "yes I will" (.) so

**INT** so they're holding the wake here then?

**Mary** they're holding tea (.) yeah one or two of 'em do after they've had t'burial y' know

**INT** yeah

**Mary** in t' downstairs where hairdresser was

**INT** is that so residents can go and

**Mary** if they're invited some of 'em yeah

**INT** yeah (.) so they invited some of the residents that were friends (.) right

**Mary** she were nice old (other resident's name) very nice (.) but it (.) she were bless (.) it were a blessing really she couldn't see at finish y' know (.) she had to be fed (.) she couldn't see what she were eating or (.) anything (.) it's awful y' know init

Mary's account of the death of her friend was portrayed to be a blessing that released her from her ageing body and put an end to her suffering. Such rhetoric is explored further in theme 2.1 'Blame and the ageing body'.

This sub-theme shows residents' desire to care about others expressed through talk of their friendship with fellow residents and their relatives. However,

investing in such relationships comes at an emotional cost: that of grief due to death of another resident that is an inevitable part of daily life in the nursing home community. How residents deal with this tension is described further in theme 3.2.

### *Care Giving*

Consistent with existing theory (Goffman, 1971), during present interviews residents' portrayal of 'care-giving' was discursively anchored to their past through stories of how they had given practical assistance to others to support their physical and/or emotional needs within the context of a relationship. This is equivalent to Tronto's 'care-giving'. Of the three residents that talked in most detail about 'care-giving', each did so for significant others at the end of life.

Harry recalls how difficult it was being the main 'care-giver' looking after his father at home until he died one night while sharing Harry's own bed:

#### **Extract 1**

**Harry NURSING HOME1 R2 L193-L200** mostly my parents (.) they were both they weren't very well (.) my mother had her leg off (.) (inaudible) (.) and my father had Alzheimers (.) you know what that is don't yer?

**INT** hmm

**Harry** anyway (.) it was nasty (.) it weren't too bad but er ..it was in his mind someone was out to kill him (.) so I had to take him in the back row with me (.) in my bed (.) he slept with me but it was only a single bed (.) but er (.) anyhow (.) oh it must be quite a few years that (.) he kept on going(.) and then just woke up one day an' (.) he were gone

Jessy referred to her bedside vigil with her husband while living in the nursing home as being physically as well as emotionally difficult for her, and positions enduring her own physical pain as being worth it to give care to her husband when he needed it:



## Extract 2

**Jessy NURSING HOME1 R3 L220-227** I stayed with him all day ..... well he didn't realise how ill he was (.) and er (2) he were sat watching me (.) and he kept sayin' "why don't you go to bed" (.) he was sat in his wheelchair (.) so I says "oh no (.) I'll stop wi yer" (.) he says "I'd rather you go to bed" (.) so I says "I'm alright" but nobody knows the pain I was in (.) I've five broken vertebrae (1) I had then an' it was one of those straight chairs (.) y'know those little chairs not an easy chair (.) and however I sat I don't know

Hilda also talks of care-giving by simply sitting with her friend in the nursing home, which is the extent to which her current ageing body is able to provide practical support.

## Extract 3

**Hilda NURSING HOME3R2 L196-L197** yeah (.) she's been seriously ill (.) anyway er (1) I've always I've always cared for (**resident's name**) (2) wherever (**resident's name**)'s gone I've gone (.) I've sat at the side of her

Below, Mary describes not being able to give care to her husband when he died in hospital and expressed regret at not being able to be there for him. Consistent with older people living in institutional care (Gubrium et al. 1999), Mary placed blame externally using her residence in the nursing home as a discursive anchor for her negative views of aging, which were objectified through attributing further blame to her own failing body: having recently experienced a stroke:

## Extract 4

**Mary NURSING HOME2 R4 L10-L11** after I came out of hospital (having had a stroke) and he died a month after I had mi stroke mi husband (1) and I weren't with him to tell you t' truth when it happened (1) which I didn't like .. **L157-L162** cos I couldn't see him (.) I went down to see him just after he died (.) but they (.) nurse had to take me and I were that (.) I weren't even safe y' know because they had to put a thing at t' front of me (.) in case I fell (2) (**Mary sneezes**) oh dear excuse me (3) but that were all I mean I didn't see him (.) he were in a month (.) and I don't think he re (.) I think he went a bit funny because I (.) they didn't say he asked for me (.) y' know and we'd been together all that time and I looked after him

**INT:** hmmm (3)

**Mary:** but we had a damn good marriage y' know

Here, residents demonstrated a moral desire to give care to others even when they were equally incapacitated and dependent on others for care, which appeared to enhance residents' self-worth. This aligns with Jacobson's (2009) human taxonomy of dignity, and definitions of Personhood (Kitwood, 1997; McCormack, 2004) outlined in Chapter 1. Residents also strove to give care in any way they are able within the constraints of their ageing bodies, and where they were now unable to care, positioned blame as beyond their control: which is consistent with previous theory (Goffman, 1971) and research (Gubrium, 1999):

### *Care Receiving*

Most residents that commented on the care they receive within the nursing home mentioned the support they got for their physical care needs. The physical care needs that residents talked of being met included basic needs such as hygiene, food, and assistance with mobility both during the day and at overnight. Typical of most residents interviewed, Vera talked of her personal care, and placed particular emphasis on the care she received around maintaining personal hygiene:

### **Extract 1**

**Vera: NURSING HOME3 R6 L40-L43** I wake up in the mornin' an' er (.) there's a carer there (.) and they get mi ready (3) then er (2) they wash me an' that an' er (.) another day I might might be going to have er (.) a bath (.) and you go and have a bath (.) but er more often than not it's just er in a morning (.) but they do keep me (.) clean (4)

Even residents that experienced dementia (i.e., Annie), were able to articulate the support received for their physical care needs, and express their satisfaction:

## Extract 2

**Annie: NURSING HOME3 R3 L275** and they (.) they help me to bed at night and put me in bed an' (.) I'm alright love

Even residents that position themselves as never having anything wrong with them acknowledged the need for support with physical needs, which is consistent with previous findings (e.g., Marini, 1999). For instance, Pat (below) described needing support due to her bad chest and needing the toilet during the night:

## Extract 3

**Pat: NURSING HOME2 R1 L585-L590** oh (.) I (.) I get a lot of (.) oh I said I've never had anything wrong with mi (.) I've developed a lot of phlegm (.) you know when I lay down flat

**INT:** yeah

**Pat:** and I just (.) my mouth just fills up with it (.) I've to spit it out and of course (2) I have the toilet (.) if I want to go to the toilet.

During interviews residents that experienced problems with falls or immobility made some reference to safety, either for them, or for staff during the delivery of care. Here Molly talked of nursing home staff keeping her safe by walking with to her room after bathing. Safety was the main reason Molly (and most other residents), cited as the main reason for moving into a nursing home.

## Extract 4

**Molly: NURSING HOME1 R5 L188-L191** I mean whoever's on nights that (.) y' know I never know I don't know their names because there's so many of them y' know what I mean (.) and that but they all are ever so nice every one (.) they're really helpful (.) they make you y' know they always come back with me to make sure that I'm (.) I'm safe heh heh (.) y' know yes (.) oh yes (.) hmm (.) I like it hmm

Similarly, Betty acknowledged that nursing home carers sometimes use moving and handling equipment in order to safely support residents' physical care

needs, such as hoists: Betty felt hoists were a significant part of care delivery as she chose to take a photograph herself of a hoist to talk about in the research interview (see photograph 5). Similar risk aversion is as a pre-requisite in models of care, such as Nolan's sense of security (2006). However, it is necessary ensure the systematic paternalism within Health and Social Care services does not constrain residents' autonomy (Dunn, 2014: Richards et. al., 2015), not least because it has failed to prevent an increase in Accident and Emergency attendance by over 80's in England (Age UK, 2019).

### **Extract 5**

#### **Betty: NURSING HOME1 R4 L19-L37**

**INT:** there's one photograph here I that I'm interested that you took (.) do you mind describing what it is for me?

**Betty:** (3) it's the top of the stairs where all the apparatus is (.) it's for lifting people out of bed (1) top of the stairs (1) out there (1) y'know y'know where that is don't yer?

**INT:** yeah (.) yeah just at top of the stairs

**Betty:** that's what that is

**INT:** was there any particular reason that you that you em (.) decided to take that one?

**Betty:** I thought it might interest you (.) they have to have (.) y'know things (.) if people are very heavy (.) they need these to lift 'em to and fro

**Photograph 5: Hoist in the corridor taken by Betty**



In addition to receiving care from nursing home staff, residents with family support also talk of the practical help they received from them: for example, Jessy's family provided a mini-fridge to enable her to have access to foods she liked when in her own room. Although this affords Jessy some independence, she still had to ask someone to pass her the food as she had difficulty mobilising. This highlights that even where residents had family and friends to support them and make small changes to promote independence, they remained dependent upon nursing home staff to fulfil even the smallest activity of daily living.

## Extract 6

**Jessy: NURSING HOME1 R3 L520-522...(referring to 1<sup>st</sup> daughter talking)** “has our (2<sup>nd</sup> daughter’s name) mentioned it to yer about havin’ a fridge?” (.) I said “yes” (.) she said “oh” she says “well I’ve got yer one” heh heh (.) as quick as that (.) that’s my family

Resident dependency can make it difficult for carers to deal with (Nicolson, 2001), which is exacerbated by need for more psychosocial training for staff, the aim of which is to improve the quality of care delivered (e.g., Dunn, 2014; and Maben et. al, 2010). The need for psychosocial care is supported where present nursing home residents suggest care required non-physical interactions with staff. Most frequently residents referred to interactions where staff engaged humour while assisting residents with their physical care needs, for example, Hilda’s account below where she affectionately referred to her bedroom as ‘the laughing room’.

## Extract 7

**Hilda: NURSING HOME3 R2 L648-L651**

**INT:** so what makes a wonderful carer then (.) I’m interested

**Hilda:** I can’t sit on t’ toilet (.) on mi own (.) you have to be in a machine (1) what do you call it a coaster or something? (.) they bring that up an’ er (1) she they they have a laugh really they bring that up an’ er (1) she they they have a laugh really (1) er when when I’ve been (**referring to having her bowels opened**) hah hah hah heh (.) heh hehh heh (.) they say (.) “pew” (.) heh heh (.) one day (.) there were two came up (.) put their fingers over it ( hah hah hah hah hah hah hah

**INT:** put their fingers on their noses did they heh heh heh heh

**Hilda:** heh heh heh heh (.) well I (.) I screamed heh heh ho ho ho

**INT:** heh heh heh heh (.) you screamed did yer (.) wi laughing

**Hilda:** ho ho ho ho ho hoh (.) I says “it’s not as bad as that” heh heh heh heh hah hah hah hah hah hah hah (.) but they are (.) they are good

**INT:** yeah (.) you don’t mind ‘em having a joke then?

**Hilda:** OH NO (.) no (1) heh heh heh heh heh (.) it’s a laughing room this heh heh heh heh heh heh

In contrast, Nancy refers to one of her carers as having a 'vulgar' sense of humour (similar to that expressed by Hilda as being enjoyable), but for Nancy such humour was incompatible with her own and affected her to the point where she was both irritated by it and wished that particular carer didn't work there.

#### **Extract 8**

**Nancy:** **NURSING HOME3 R7 L226 –L232** the staff on the whole (.) the staff are very very discreet (1) I've grumbled to some of them about (.) her (**a particular carer**) and (2) I didn't realise until a month or two ago (9.0) that she irritates the staff as much as she irritates me

**INT:** oh right (1)

**Nancy:** but I wish she weren't here (.) (inaudible)

**INT:** hmmm (7)

**Nancy:** she tends to see the (.) the vulgar side of things (.) and tends to tell jokes

In summary, present findings suggest residents perceive care-receiving as necessary for their own safety but are also conscious of the safety of staff when delivering that care. Physical care is important to residents, but there are subtle differences between the priority individual residents place on the nature of this, and the emotional care they receive. The care-giver's sense of humour lightens the mood for some residents when receiving support with their physical needs. However, staff humour must be compatible with that of residents to maintain emotional harmony for all concerned. For other residents, the key to making care-receiving bearable is the discretion of care-givers. Thus, staff must understand not only residents' physical care needs, but also their disposition and emotional care needs. Such holistic (biopsychosocial) care is consistent models developed for institutional care for older people (e.g., Chochinov; 2007; McCormack, 2006,2011; and Nolan, 2006).

### ***Sub-theme 1.2: Care obligations and contradictions***

In Theme 1.1 findings from resident interview transcripts revealed that residents portrayed 'care' in three ways: caring about, care giving and care receiving and also talk of the relationship contexts in which this care exists (family, friends and formal carers). I also found that residents describe each type of care, and the relationship context in which it exists, as being given or received either conditionally or unconditionally. Residents' talk suggests they 'care for', 'care about' and 'care give' to their family and closest friends unconditionally. However, 'caring for', 'caring about' and 'care giving' to casual friends or formal carers exists only when certain conditions are met. As an aid to the reader, table (8) below outlines how residents tended to portray the care relationships they have with others.

**Table 8: Care relationships: Conditional and Unconditional Caring, Care-giving and Care-receiving**

How residents portray the care relationships they have with others		Resident's Family		Resident's Friends		Nursing Home Staff	
PERSON ACTING	CARE TYPE	C	U	C	U	C	U
Resident	Care about		Y	Y	Y	Y	
	Care giving		Y	Y	Y	Y	
	Care receiving	Y		Y		Y	
C = Conditional    U = Unconditional							

#### ***1.2a) Unconditional 'caring about/for' others***

Residents' rhetoric suggests they 'cared about' others through acts of 'care-giving' that residents portrayed as being given by them to others unconditionally.



Examples included supporting their children by caring for grandchildren (Fred), and sacrificing getting married to provide financially for parents (Harry)

**Fred: NURSING HOME1 R1 L341-343** cos they (daughter and son in law) went out to work you see as things was and I wasn't workin' so every morning I picked him (grandson) up, went to their house, and I had him and I let her have my car to go on a course

**Harry: NURSING HOME1 R2 L162-L168:**

**Harry:** I've never been married

**INT:** you've never been married (.) was there a reason?

**Harry:** my parents (.) when I came out of the war I was (.) about thirty I think (.) thirty I think I was thirty (.) I went in at 24 and came out at 30 (.) and then I had a house (.) I had an extra year in (.) because in that time (.) the (.) the unemployed was over a million people (.) and so I said I'll stay in for another year (.) so that I could get my money (.) and money was also sent on to my parents y' see

Within the context of the interview residents' self-sacrifice placed them in an ideologically positive light. Residents also talked positively about people close to them (relatives and friends) or liked by them (some nursing home staff) by positioning significant others as 'caring about' them unconditionally. For example, Jessy and Molly (below) speak highly of the attention they receive from their families:

**Jessy: NURSING HOME1 R3 L497-L506** oh yes (2) we can have as many visitors as we wish (.) any time any day (.) and well my daughters (.) they come often ...they come to see me and that's the main thing (.) yeahh (.) and if I need anything (1) "why didn't you tell me I could've brought yer" (.) y' know

**Molly: NURSING HOME1 R5 L332-L348**...my nephew who did all I telled yer the business of me coming in here (.) well and then well it took some weeks (.) a few month actually (.) for my business to be settled (.) but he used to come over and see me if there were forms I'd got to sign ... well he did that regularly (.) until (.) everything was settled y' see (.) and that so (.) oooooh he was wonderful (.) I don't know what I'd have done without him (.) mind you one of the others in the family would have done the same (.) y' see they're all marvellous.

Similarly, in the following example, Mary's daughter telephones during the interview to enquire about her mother's forthcoming operation, which enables

Mary to indirectly give an account of how attentive her family are to her care needs:

### **RESIDENT'S PHONE IN HER ROOM RINGS AND RESIDENT ANSWERS**

**Mary: NURSING HOME2 R4 L27-L33** oh dear

**INT:** that's ok let's just pause that

**Mary:** mi daughter she's on t' phone I bet (.) (**recorder paused for duration of personal call**) that were mi daughter she wants to know what time I'm going tomorrow cos I'm having mi eye done (.) I've got cataracts y'know (1) and they're doing this eye tomorrow when I (.) so I'll probably have a patch tomorrow

Portraying significant others as aligned with the residents' own morals and values relating to 'care' added value to residents' own credibility, as it demonstrated residents had passed on these positive values. However, residents sometimes described their loved one demonstrating uncaring attitudes or failing to be good care-givers. For example, Betty talks of her daughter pressuring her to go into nursing home despite feeling she could have managed in her own home. When Betty lived at home her daughter had demonstrated she 'cared about' her, and was a good 'care-giver' by filling her freezer for her, but her daughter's caring/care-giving role is now portrayed as obsolete:

**Betty: NURSING HOME1 R4 L7-L11**

**INT:** what em led you to coming in the home in the first place?

**Betty:** my daughter thought I wasn't managing very well (3) but I think I'm (.) I think I could have done (1) anyway (.) house is sold (.) it's gone (.) house is gone (.) and now I'm here (3)

**INT:** but you thought you could have managed?

**Betty:** well I think I could (2) I'd got this oxygen piped in the house (.) I'd got stair lift (1) so ... **L204-L206** oh yeah (.) I paid for a cleaner 'n' (.) paid for a gardener (3) I have somebody come and do mi shoppin' (.) you know odds and ends (.) but when (**daughter's name**) comes she used to stock fridge freezer up (.) but I don't have to do that now

Such positioning is similar to the 'in-groups' and 'out-groups' of Tajfel's (1979) integrative theory of intergroup conflict (ITIC). In such scenarios where

relatives behaved outside family group norms, residents justified the undesirable behaviours by anchoring them externally to social or economic pressures beyond their loved one's control: for example, having to work leaving insufficient time to be a care-giver. Such positioning/justification reflects the intrapersonal level of storytelling that is used to take control and bring order to the world during times of disruption (Murray, 2000; Ricoeur, 1979; and Stephens, 2011). Similarly, Hilda talks of having visits to the nursing home, but not from her grandson's wife, which was justified because she was pregnant:

**Hilda: NURSING HOME3 R2** oh I get mi two sons comes (.) er (4) mi two sons but not mi grandsons' wife (.) she's expecting another baby

Below, Mary uses the work ethic and commitments of her children to excuse them from taking care of her in their own home, and for her son visiting her less than her daughter:

**Mary: NURSING HOME2 R4 L8-L9** well mi daughter were working and she'd got a mortgage o she couldn't give it up (.) so they brought me in here (.) after I came out of hospital ... **L209-L210** I see mi daughter regular but mi son I only see him at Sunday (.) he works away all t' time

For Jessy, the reason her children can't accommodate her is due having insufficient space, having to seek work, and other caring commitments:

**Jessy: NURSING HOME1 R3 L498-L506** if they (daughters) could accommodate me (.) they would (.) but they can't (.) erm (**daughter 1 name**) comes from **Nearby Town Name** (.) she's a (.) her husband's disabled (.) but erm she she's still looking for work (.) but as I say (.) she (.) her daughter's at home (.) and it's only a two bedroom bungalow (.) theirs (.) and er (2) (**daughter 2 name**) lives in a flat (.) three storeys (.) so she can't accommodate me ....I couldn't manage the stairs (.) I couldn't so (.) it's no good

### *1.2b) Conditional Care-giving by/for residents*

Despite positioning themselves as 'caring about' and 'care-giving' unconditionally for family or friends, there were contradictions in residents' talk

where they would sometimes refer to themselves receiving something in return, albeit unintended. Here, Fred described caring for a close friend, managing her financial affairs after her death, and receiving an inheritance. This suggests that caring and managing his friend's finances was conditional upon receiving something in return, or equally that his friend felt obligated to give him something in exchange for his good deeds:

**Fred: NURSING HOME1 R1 L517** she (**friends name**) couldn't swallow she couldn't eat n' that y'know (1) cancer of the throat (.) sudden (.) yeah yeah (.) very sudden (.) and I was the only one she had no relatives ....so I had to distribute and er sell the house and everything like that y'know (1) She left me quite a bit like y'know.

Here, Harry tearfully talks of feeling happy yet obliged to care for his parents as they had cared for him.

**Harry: NURSING HOME1 R2 L208-209**

**INT:** so you cared for your parents for a long time did yer?

**Harry** hmm (.) oh a good many years yes (.) but I didn't mind (.) they'd cared for me so .....**HARRY BECAME TEARFUL**

Here, Doris gives her account of living with and losing her parents and then her aunt living with her, all after Doris had already retired from a caring profession. When asked if she cared for her aunt she disclosed that she did, but also received care from her aunt in return.

**Doris NURSING HOME1 R6 L153-164** I lost mi mother (.) and then there was just dad and I and er (1) and then aunty (.) I'd two aunties (.) that we (.) mother's sisters (.) and er (1) one of those had died (.) so the other one decided (.) and then dad passed away (.) so this other auntie came and she lived to be ninety (.) nearly a hundred

**INT:** with you?

**Doris** yeah

**INT:** did you care for her?

**Doris** yes (.) she cared for me as well (.) yes yeah we were (1) yes we were very happy together (.) hmm (.) so that's me (.) story of mi lifetime up to now heh heh

These examples are consistent with Tronto's Ethic of Care that suggests care-giving/receiving is cyclical, contractual, and thus conditional in nature. For residents 'caring about' those beyond family and close friend relationships was usually conditional upon the individuals concerned having compatible dispositions, which has been previously described in Theme 1.1a) (Relationships), where residents talk includes examples of their relationship with other residents and with nursing home staff. Similarly, when residents perceived nursing home care staff as 'caring about' them unconditionally, they also positioned the staff as having a disposition or care values compatible with their own. This mirrors views of participating nursing home staff (see Chapter 4), as residents and staff each position care-giving and care-receiving that is delivered by 'in-groups' as being positive, and that delivered by 'out-groups' as being negative: which aligns with the positioning of Tajfel's (1979) integrative theory of intergroup conflict. For example, Pat (who had been in the nursing home for 84 weeks) talked of her fondness for a particular male carer, despite previously stating that she preferred having female carers for assistance with personal care. She made an exception because he shared her values of having a kind and generous disposition. Pat recalls that while escorting her on a hospital appointment this male carer demonstrated unconditional 'caring-about' and 'care-giving' to a stranger:

**Pat NURSING HOME2 L676-685** well we came through that door at the she (.) and as we came through there was a (.) an elderly lady (2) looking very old (.) in a wheelchair (.) long (.) so she probably couldn't walk (.) and she was looking round (.) as if she was looking for someone (.) and he went to her straight away (.) and he said to her (.) "are you looking for somebody can I help you (.) are you looking for somebody?" and I thought (.) what a marvellous (.) now those sort of things (.) I appreciate (.) and I thought it was wonderful (.) and he's only just an ordinary man (2) and I thought (.) oh dear (1) what a wonderful man (.) he came back and ever since (.) I've always had if you like to call it (.) a yen for him (.) I don't mean a love yen (.) I don't mean that (1) but (1) he he he does things for you (.)

in fact he got me up this morning and (.) got me out of bed (.) and you know things like that (.) I don't get him every morning (.) because (.) actually he got an advancement for himself

**INT:** right

**Pat:** and er (.) I can quite appreciate that (2) but he he just (.) others don't do it (2) not like that

In contrast, Kath (who had only been in the nursing home for 3 weeks compared to Pat's 84 weeks) described the disposition of carers as mainly 'alright', but also as variable with some described as not speaking to her.

### **Kath NURSING HOME3 L252-257**

**INT:** yeah (3) what are the staff like then?

**Kath:** alright you do get the odd one but y' know what I mean .. not an odd one I mean that er (.) some of 'em will speak and others won't y' know what I mean

**INT:** yeah

Such negative interactions represented poor care from residents' perspectives. Usually when residents described negative care interactions with nursing home staff, the disposition and care values of the staff member was portrayed as un-compatible with that of the resident, just as with their relationship with other residents (see Theme 1.1a Care Relationships). In such scenarios, residents describe the care they receive from staff as conditional upon residents giving something in return; this included feeling obliged to change their behaviour including becoming compliant and/or passive. According to Crossley (2010:17) such passivity represents objectification where people become marginalised by the power of health professionals. For example, Fred described how his attempt at independence by moving his bedroom furniture around to suit him was met with confrontation by cleaning staff who said it was against the rules and he needed permission. Fred experienced being shunned by the cleaner in charge for failing to comply with the nursing home conditions (rules) for care-giving, but

says he has developed a thick skin in response to being ignored by this staff member.

**Fred NURSING HOME1 R1 L453-L486** “her (cleaner) in charge didn't like it, little cocky and she comes bounding in like 'that bed shouldn't be there'. I said that bed's staying there, I'm livin' here this is my house. She says 'I want it t'bi here put it bi there'. I said "don't be stupid"...she didn't like it...she run out and ever since she's ignored mi and she's gone tellin' t' tale I know she has, I know she has I'm not bothered about that”

Similarly, in the following three extracts Nancy's story demonstrate how she had adapted her behaviour in response to carers whose disposition and care values were incompatible with her own. The pressure residents feel to change their behaviour fails to comply with all of models of care for older people previously described (Chochinov; 2007; Kitwood; 1997; McCormack, 2006;2011; Nolan, 2004). In extract 1 Nancy describes her ideal care-giver; in extract 2 she recalls her first day in the nursing home, how she regretted not complaining about the poor care she received, and how she felt disempowered: referring to herself as “the new girl”; and in extract 3 Nancy gives her account of how she has learned to cope with receiving care in the nursing home by becoming passive and compliant:

#### **Extract1: Nancy's story NURSING HOME3 R7 L93-L95**

**INT:** so what qualities would you say that a good nurse or a good carer has that makes a difference?

**Nancy:** empathy with the patient (3) an acceptance of (1) loss of ability of the patient (7) I can't think of anything else really (2) that's that's it (2)

#### **Extract 2: Nancy's story NURSING HOME3 R7 L132-L162**

**INT:** so (2) here you are now in the home (.) it looks like your daughter (.) made the decision (.) did you get to see the home before you came?

**Nancy:** no

**INT:** did you have a trial or anything?

**Nancy:** I didn't

**INT:** right (3) so what were your first impressions then?

**Nancy:** (6) bad (3) I was in the room opposite (.) with another woman (.) sharing

**INT:** oh right

**Nancy:** she never spoke (3) and the first morning (3) I was getting dressed (2) I was being dressed (2) and I had a physical fight (1) with the helper (2) she was forcing me to put a shirt on which I didn't want (1) and I said to her "this is bullying" (2) and I don't know what she said (.) but she was like a tank she didn't stop (5) I've been depressed (2) I don't think I'm depressed now (1) but I have been in the past (5)

**INT:** so how did you (1) negotiate that (.) feeling of being bullied what did you feel you could do?

**Nancy:** I couldn't do anything (2) it was (.) I was too much of a new girl (.) to (.) speak to management (2) I think it was great mistake (.) yeah (.) but the manager is a business manager (.) she had no experience of care (1) and I think they should have two (.) one business (.) one in charge of caring staff (1) it must be three or four times a week I'm told "we're short staffed (1) we've only got one down here" (.) this is true (.) but I think (1) they're paying £5.50 an hour (1) and (2) I just think they need more staff (6) when I think (.) how dependent I am (4) maybe I'm (4) they do support me they do keep me (2) keep me alive (3) and erm (2) watered and fed (10)

**INT:** is that enough? (5)

**Nancy:** it's about it (2)

**INT:** I mean is that enough for you? (3)

**Nancy:** No (2) there are one or two (.) who are unfailingly kind (.) and patient (3) and there are some patchy (.) different moods (9) but I need more help here than I did when I had help (.) carers would come in three times a day (5)

**INT:** so did you say you get (.) about the same or more care here?

**Nancy:** you get more care here (2)

**INT:** and that's why you (.) came here

**Nancy:** overnight care

Next, Nancy talks of some carers being good and others not so good (immature), and describes how she has adapted to receiving care by responding to the individual carer: sometimes she resists, but usually perceives carers to be too strong and instead becomes passive: she said "*I let the unpleasantness roll over me*":



### **Extract 3: Nancy's story NURSING HOME3 R7 L166 – L190**

**INT:** you've got one of the carers that's perhaps extremely kind (.) like you said (.) and then you've got one of the carers (.) who can be changeable (.) depending on their mood (.) how does that make you feel depending on which carer you get (.) how does that affect you? (22)

**Nancy:** I make myself (.) more passive (2) but not always (8) (I tell myself) it's not so bad (2)(besides) (3) the other day I told him "you're behaving very badly" (1) and he said straight back at me "so are you"

**INT:** sorry?

Nancy he said "so are you"

**INT:** he said that to you?

**Nancy:** yes (2) he's erm (.) on the other hand (1) he can be very can be very caring (4) but he's very immature (.) it's like dealing with a teenager

**INT:** hmmm

**Nancy:** (and I treat him) like that .....

**INT:** and how you manage to (.) what you do to adapt depending on which carer it is (.) and you said that you become more passive I think is what you said (2)

**Nancy:** I let the unpleasantness roll over me

**INT:** right (9)

**Nancy:** I think (3) oh I (.) they all seem to appear very strong (20)

Whether or not residents described individual care staff as having a 'caring disposition,' they portrayed 'care-giving' by nursing home carers as being conditional upon receiving a reward, for example, receiving wages. Residents sometimes positioned shortcomings in the care they received as external to care staff, and blamed it on management and care staff having to endure long hours, staff shortages and low pay. This is consistent with previous findings of the inadequacy of rationalised care (Brown, 2008; Carpenter, 2008; Dunn, 2014; Kerr, 2008; McCloskey, 2007; RCN, 2010; and Sheffield LINK, 2011) that fails to meet the requirements of dignity conserving, 'relationship-centred' care that is

advocated in older peoples care settings (see definitions and models of care in Chapter 1).

This can be seen in the context of Nancy's previous account (extract 2: Nancy's story NURSING HOME3 R7 L132-L162) that is also repeated in part below, where she feels inadequate management and pay and conditions for staff impacts negatively on the quality of care she receives:

**Nancy: NURSING HOME3 R7 L147-L141** "but the manager is a business manager (.) she had no experience of care (1) and I think they should have two (.) one business (.) one in charge of caring staff (1) it must be three or four times a week I'm told "we're short staffed (1) we've only got one down here" (.) this is true (.) but I think (1) they're paying £5.50 an hour (1) and (2) I just think they need more staff

The negative impact on resident care due to inadequate investment in resources at organisational level and beyond is supported further in other resident's accounts. For example, Mary describes how support from nursing home care staff to improve her mobility following a stroke is conditional upon staff having time to help her walk, which is rare due to staff shortages. Mary felt she is not receiving the level of care she should for her rehabilitation within the nursing home, which mirrors findings of a failure to deliver specialist NHS services (including Physiotherapy) within care homes for older people (Sheffield LINK, 2011).

**Mary: NURSING HOME2 R4 L12-L24** I were paralysed down this side (2) and it's never altered too much at all since (.) mind you we don't get no physios in here y' know and you should do really I think every home should have one

**INT:** hmmm (3)

**Mary:** I used to have one I paid for one at first (.) but it were fifty pound an hour and went up to sixty pounds (.) so I stopped it off (1) thought it were a bit much that sixty pound an hour (2)

**INT:** is that while you were in here?

**Mary:** yeah while I were in here yeah (1) they were good wi mi they helped me walk (**referring to paid physiotherapists**) I could walk wi somebody at one side o' me t' top o' passage and back (.) when they were wi mi (.) these (.) physios (1) but after they stopped there's no (.) there int enough staff here to help yer y' know they're always too busy (3) that's mi only complaint really

This sub-theme highlights that residents considered receiving care themselves to be conditional, and expressed a perceived moral obligation to compensate the care-giver in some way. This finding is described in more depth in the following sub-theme (1.3).

### ***Sub-theme 1.3 Care currency: Two-way transaction***

For residents caring was portrayed as being a two-way transaction or contract that required both parties to contribute to the relationship: the first party being the care-giver (i.e., nursing home institution and individual nursing home staff), and the second party being the care recipient (i.e., residents themselves). This aligns with relationship focused theories and models of care previously presented in Chapter 1.

#### ***1.3a) Expectations of care***

In this sub-theme presents what residents wanted to receive from both the nursing home organisation and individuals (e.g., nursing home staff) in accordance with their representation of care as being a two-way care transaction. What residents expected from the nursing home itself was adequate resources for staff to be able to perform their care-giver role adequately: they expected value for money regardless of whether residents' care was privately funded. A number of examples were given by residents of how inadequate resources at organisation level impact negatively on the care they received in all three participating nursing homes. Residents' accounts mirror findings of Study 1

(Observation Study) and Study 2 (Staff Focus Group) that were presented in chapter 3 and 4 respectively.

In extract (a) 1, Mary describes how despite positive efforts by the nursing home manager, insufficient resources can make the difference between a good and a bad day. This supports concerns that profit margins may compromise the quality (Francis Report, 2013; Schlesinger et al., 1984: and Shadish, 1989) and consistency (Beckford, 2011; Royal College of Nursing [RCN], 2010) of nursing home care.

**Extract (a) 1: Mary NURSING HOME2 R4 L54-L64**

**Mary:** yeah it's very nice in here (.) got some good staff (.) she's altering it round a bit (**matron's name**) (.) she's moving staff upstairs to some from upstairs down (.) so that they go round a bit (.) it's quite good (1) we have bad days and good days ' now (.) like everywhere else (3)

**INT:** what would you consider to be a bad day or a good day then?

**Mary:** well sometimes there's not enough staff on (1) and sometimes there might be just one (.) regular staff and an agency (.) and most o' agencies 'aven't a clue what to do when they come in (1) they're not very good really (1) so it makes it hard work for hem ' know (1) so you don't get as much done as you should do (.) you could be waiting ages (.) sometimes when it's like that you ring for a bed pan you could be waiting ages whey you've time to wee yourself bi t' time they get here

**INT:** hmm

**Mary:** which is not very nice (1) I'd better shut up 'ant I

Mary concludes by saying that she should have a passive voice and not complain ("I'd better shut up"), which is an attribute residents adopt to placate nursing home staff, and consider to be their 'required' contribution to the 2-way 'care' transaction (see below 1.3b). Residents' accounts, along with findings during Study 1 (observations) and Study 2 (staff focus group) support Crossley's (2010) argument that people (patients) become the passive 'object' of powerful

medical experts or those in a position of power over them: such as nursing home staff. This dominance by nursing home staff over residents contravenes the principles of personhood, and person-centred dignity conserving care that is recommended for older peoples' institutional care (e.g., Brown, 2008; Kitwood, 1997; McCormack, 2004, McCormack & McCance, 2006; Nolan, 2001; Nolan et al., 2004, 2006; and Ryan, 2008).

When asked what represented a good day, Mary (extract [a] 2), spoke of sufficient resources being available to meet all resident's basic care needs, with additional resources for extra-curricular activities:

**Extract (a) 2: Mary NURSING HOME2 R4 L65-L78**

**INT:** what (.) the other way what would be a good day then?

**Mary:** well it is ( ) everything goes smooth it's a good day (.) sometimes (.) when (**staff name**)'s on (.) she's activity lady (.) we have tombola Tuesday and Thursday (.) and we've got some trips (.) so they take us out y' know certain days (.) in fact I've got a list of trips but I don't know where they are now (.) we go down t' (1) we're not gonna t' seaside this year (.) we usually go t' seaside but they're not going money's running short I think (1) but they go t' garden centres an (.) different places (.) take yer (1) and' that's nice (.) other week one o' t' sisters too me to (**town name**) market it were lovely (1) a real lovely day 'n' all when we went (1) them's things that happen ere y' know

**INT:** did she take you as an organised (.) thing

**Mary:** yeah

**INT:** through the home then?

**Mary:** yeah yeah they take yer and you go in an' you have coffee an' whatever you want y' know (.) when you go out fo' t' day to these things (1) quite good really when you go (1) nice day out (.) a change from being in here all t' time

What residents expected from nursing home staff was consistent with literature outlining the characteristics of a good care-giver (e.g., Chochinov, 2007; McCormack, 2006; Nolan, 2006; and Tronto, 1993;1998). For example, residents required staff to: be devoted to their work, but also approachable (extract (b) 1

Jessy); show affection and kindness (extract (b) 2a Hilda and 2b Annie); listen to residents, speak to them, and treat them with respect (extract (b) 3a Betty and 3b Kath); understand the residents' current physical and emotional limitations (extract (b) 4: Nancy); and have knowledge and experience to deliver the care preferences of individual residents (extract (b) 5: Mary). Most residents enjoyed staff having a sense of humour, as long as staff appreciated where, when and how it was appropriate to use it. This was detailed previously in Theme 1.1b 'Care types' with examples from Hilda (extract 7) and Nancy (extract 8). Residents wanted staff, including the nursing home manager to be dedicated to their work, but still approachable:

#### **Extract (b) 1: Jessy NURSING HOME1 R3 L736-L744**

**Jessy:** she's a wonderful woman (.) (**matron's maiden name**) (.) yes..... yes (.) her name's Mrs (**matron's surname**) (.) but she's known to everyone as (**matron's maiden name**)

**INT:** yeah

**Jessy:** well she signs herself (**matron's maiden name**) (.) she does yeah (.) she's (.) devoted (1) to her work (.)

Residents also enjoyed it when staff showed them affection and kindness:

#### **Extract (b) 2a Hilda NURSING HOME3 R2 L338-L354**

**Hilda:** no but they're very good (**carers**) I couldn't wish for a better place (2) I'm quite happy here (3) and (**favourite carer's name**) that came in (.) she thinks the world of me.. L354 yeah (.) I think the world of her (2)

**INT:** hmm (2) and now you're here (.) what (.) what's the thing you like best (1) about being here? (2)

#### **Extract (b) 2b: Annie NURSING HOME3 R3: L180:L181**

**Annie:** way I like the company (2) I like the company it's alright (.) here (.) it's alright in here (2) they're good ter mi (.) they're good (.) that's main thing int it?

Aligned with models and theories of care (Chochinov; 2007; Kitwood, 1997; Nolan, 2006; McCormack; 2006; and Tronto; 1999) and existing literature (e.g., Brown, 2007; and Mitchell, 2015), participating residents wanted carers to treat them with respect to facilitate a relationship based on trust: this included listening to residents, and talking to them:

**Extract (b) 3a: Betty NURSING HOME1 R4 L38-L40 and L76-L84**

**L38-L40**

**INT:** so what's your (.) what's your idea of what for you personally would be good care (.) what's your ideal? (2) for you? (2)

**Betty:** one person listening to another person ... **L76-L84** I don't know who to trust (4) coming up in the lift (.) a gang of girls going down (.) all that work up here (.) they never said a word to me

**INT:** never said a word

**Betty:** never said hello

**INT:** that right (.) not even hello

**Betty:** no (.) and I didn't (inaudible)

**INT:** pardon?

**Betty:** and I didn't (.) well I thought if one o' them can't (.) I'm not (1) it sounds a bit petty I know but (.) now (.) an' I don't want to talk about it any more (.) alright? (1)

As we can see from Betty's closing remark, she felt uncomfortable and upset continuing to talk about circumstances where she felt ignored. Staff ignoring residents equates to 'Malignant Social Psychology' (Kitwood, 1997) and was found to undermine the personhood of older residents with dementia (Mitchel, 2015). Staff excluding Betty (and Kath below), is similar to Tajfel's (1979) out-groups where others have different interpersonal (individual) values, beliefs and behaviours to our own. In Kath's talk (extract (b) 4b) she positions staff ignoring her as being due to the individual carer's temperament. Regardless

of temperament it has been found that nursing home staff can apply Chochinov's Dignity Conserving Care (2007) principles to enhance residents' personhood (Hall, 2009).

**Extract (b) 3b: Kath NURSING HOME3 L252-L263**

**Kath:** some of 'em will speak and others won't y' know what I mean

**INT:** yeah

**Kath:** and I think it makes hell of a lot of difference that doesn't it?

**INT:** yeah (2) yeah (4) why do you think that is then (.) that some talk and some don't? (2)

**Kath:** well I don't really it's only just a matter of I think how they work (.) how they work y' know (.) I mean I suppose if you'd got (some now) they'd not both be the same would they?

Consistent with Chochinov's 'Compassion' (2007), Nolan's 'Significance' (2006), McCormack's 'Care Processes' (2006), and Tronto's 'Caring About', residents also felt it was important that carers show empathy when delivering care: Nancy suggests this requires staff to have knowledge and understanding of each resident's capacity and limitations, both physical and emotional:

**Extract (b) 4: Nancy NURSING HOME3 R7 L93-L95**

**INT:** so what qualities would you say that a good nurse or a good carer has that makes a difference?

**Nancy:** empathy with the patient (3) an acceptance of (1) loss of ability of the patient (7) I can't think of anything else really (2) that's that's it (2)

Consistent with the views of staff participating in the Staff Focus Group study (Chapter 4), Mary also suggests that staff lacking in knowledge and experience of individual residents' needs, such as agency staff, are less able to deliver the care preferences of individual residents.

**Extract (b) 5: Mary NURSING HOME2 R4 L59-L62**



**Mary:** regular staff and agency (.) and most o' agencies 'aven't a clue what to do when they come (1) they're not very good really (1) so it makes it hard work for them y'know (1) so you don't get as much done as you should (.) you could be waiting ages (.) sometimes when it's like that you ring for a bed pan you could be waiting age whey you've got time to wee yourself bi t' time they get here

This supports findings of the need for improved training of staff to enhance social care delivery (Department of Health [DOH], 2009b; CQC, 2011a): For example, through development of the Dementia Audit Tool that reviews assessment and care planning, prioritises staff training, and builds on best practice (Conroy, 2006; 2008); and action research that developed a toolkit to preserve dignity (The ENACT Project) (Gallagher, 2017).

### ***1.3b) Payment in Kind***

In return for care received from the nursing home and formal care staff, residents demonstrated a perceived obligation to give something in return. The form of currency residents described giving in exchange for 'care-received' from nursing home staff depended on the means available to them. In exchange for care-received some residents talked of having the material means to pay for nursing home fees themselves, but acknowledged that others didn't (extract (c) 1 Harry). To gain staff approval and reduce the care-giver burden on staff some residents did as much as they could for themselves (extract (c) 2 Fred), or refrained from calling for help too often (extract (c) 3 Shirley). Some residents used humour (extract (c) 4 Vera), or did all they could to promote their own health (extract (c) 5 Molly). Others talked of complying with nursing home rules (extract (c) 6 Molly) or refraining from questioning existing care practices (extract (c) 7 Nancy & extract (c) 8 Betty). Finally, some residents gave staff compliments (extract (c) 9 Harry) or small gifts such as sweets (extract (c) 10 Annie).

Consistent with findings that older people position themselves as virtuous in interviews (e.g., Williams, 2000), in this first extract Harry virtuously positions himself as having the means to pay for the care he receives within the nursing home (L115-L118), and thinks he gets value for money:

**Extract (C) 1: Harry NURSING HOME1 R1 L115-L118**

**Harry:** I pay four hundred and thirty nine pounds I think for this room (.) that includes everything food and everything (.) which is quite reasonable really

**INT:** is that for a week?

**Harry:** oh yes (.) for a week yes (.) hmm (.) cos this is a private place y' know

**INT:** yeah (.) yeah (.) so what do you get for that then (.) what (.) what's good value for that (.) what do you get for that?

**Harry:** well I've got this room (.) mi own toilet (.) the wardrobe and everything else (.) and all mi meals (.) and medical attention if you want them (.) it's very nice (.) I think it's good value (.) it's I'm quite satisfied

Later in the interview Harry describes other residents as the same as him (in-group) as they too need nursing home care, but emphasises that they are still different to him (out-group) as not all of them are able to pay for the care they receive themselves. Paying for his own care gave Harry a sense of self-worth, which is integral to maintaining human dignity (Jacobson, 2007):

**Extract (C) 1.1: Harry NURSING HOME1 R1 L554-L557**

**Harry:** they're all in the same place (.) same position as me (.) most of them here have no money (.) they've come they've got here y' know with health care (.) it used to be I think (.) for housing (.) and er they could come here even though it's private 'n' (.) I think this place has (.) for them is paid for by health care

Residents also talked of contributing to the care contract by doing as much as they could for themselves, and of gaining the esteem of staff by doing so, which seemed to be of importance for residents. By maintaining dignity-of-self

(respect and confidence) and dignity-in-relation (relationship with staff), residents are arguably promoting their health and wellbeing (Jacobson, 2007):

**Extract (c) 2: Fred NURSING HOME1 R1 L728-L729**

**Fred:** I think she (**manager**) thinks a bit about me for the simple reason I help myself as much as what anybody in here does (.) d' y' know

There was a distinct sense of the need not to over-burden staff who most residents considered to be overworked: this resulted in residents refraining from asking for help as much as possible. This supports previous findings where residents felt staff didn't have time to engage with them individually, although nursing staff preferred residents to actively seek their support (Tuckett, 2009).

**Extract (c) 3: Shirley NURSING HOME3 R5 L8-L18**

**Shirley:** aye for t' staff (.) it's hard work y' know (.) an' (.) I wouldn't like their job (.) and erm (.) but they're happy in their job y' know (.) they (.) there's nothing that they wouldn't do for yer or (.) when when (they say) "just wait five minutes" (.) and (they might even) forget yer

**INT:** yeah

**Shirley:** but you've only got to get on yer buzzer (.) an' (.) you've got em

**INT:** yeah

**Shirley** that's what I do y' know but it is awkward for 'em I don't like using t' buzzer because (.) erm (.) they might be just putting somebody on the potty (.) y' know an' the buzzer goes an' (.) they don't know which way to turn y' know

**INT:** right

**Shirley:** it is awkward for 'em

Vera also expresses her concern about over-burdening care staff when she uses her nurse call system to ask for support. To buffer the care relationship from this perceived imbalance, Vera offers humour to placate staff's displeasure at having to give too much:

#### **Extract (c) 4: Vera NURSING HOME3 R6 L123-L131**

**Vera:** they have (4) a (9) I've got that buzzer and I can buzz and ring they need to come and see what's wrong

**INT:** ok (.)

**Vera:** hmmm (3) and they'll say "what is it now?" because I always seem to be ringing y' know heh heh heh heh (.) but er (1)

**INT:** is that what they say?

**Vera:** "OH she's at it again" (.) "it's her int it again" (1) I just try and make a joke of it y' know (1) but they're really (.) they are really (.) smashing people

Other residents contribute to the care relationship by actively engaging with the nursing home community and adopting behaviour that (in accordance with Nolan, 2006; and McCormack's, 2006 models of care) promotes their own health and well-being (e.g., extract (c) 5 Molly). This also serves to reduce the care-giver burden for nursing home staff:

#### **Extract (c) 5: Molly NURSING HOME2 R5 L246-L253**

**Molly:** I mean if I should have everything that's on offer I should put too much weight on because (.) you're not doing anything to work anything off are you (.) so heh heh (.) you've got to be sensible heh heh

**INT:** so you go to exercise class

**Molly:** oh yes we do that heh heh (.) I enjoy it y' know 'n' that (.) well you're sat in you know those chairs in the dining room .. you've got to be careful you don't hit anybody next to you if you're spreading your arms out 'n' that y' know but it's alright (.) ooh I like it (.) yeah

In addition to engaging pro-actively in nursing home community activities residents also talk of the need to comply with the rules, policies and procedures of the nursing home. Some (e.g., Molly) support sanctions that restrict residents' risky lifestyle choices i.e., restrictions on smoking:

#### **Extract (c) 6: Molly NURSING HOME1 R5 L229-L231**

**Molly:** I mean to say I don't smoke I've never had a cigarette (.) and (another resident's name)...(.) I don't know whether you know her (.) she's further on the corridor (.) but er she's a smoker (.) and so of course she's got to sit out in the porch y' know

Residents seemed to accept unquestioningly, almost sub-consciously the impact that the institutional rules policies, procedures had on the physical space in which they lived:

**Extract (c) 7: Nancy NURSING HOME3 R7 L636-L644**

**Nancy:** I feel about those notices (.) I'm I'm in an institution (.) so I'm in an institution (.) and never even queried those things (.) on the wall

**INT:** hmmm

**Nancy:** never thought of it (1) cos I don't feel that this is my home (.) at all (.) this is where I am (.) and this is where I'll stop (3) but I don't care what they do how they arrange it because (3) I don't identify with it

**INT:** hmmm(1) yeah (7) do you feel that (.) there would be anything (.) that might make it feel like home (.) or do you just feel that it it wouldn't ever feel like home (.) to you

**Nancy:** never feel like home (4) because I haven't created anything

For some residents, passive acceptance that this was an institution and not their home was the stance adopted: even when, (like Betty below), they disliked something about their physical environment.

**Extract (c) 8: Betty NURSING HOME1 R4 L?-L? – extract about picture on her wall**

**INT:** did you did you bring that picture in or were they already there?

**Betty:** oh ooho no

**INT:** don't you like it?

**Betty:** I don't (2) it's not my sort of picture (.) and it's not my wall

**INT:** (4) would you not rather them take it down?

**Betty:** I'm not bothered

This passive acceptance mirrors present observation findings (see Study 1: Chapter 3) that found participating nursing homes were dominated by medical, rationalised and legislative discourses. As previously discussed, this inhibits relationship-centred care (e.g., Brown, 2008; Nolan, 2006). However, such risk averse rules arguably meet the criteria of 'Security' required within Nolan's Senses Framework. Finally, residents also spoke of contributing to the care relationship by showing staff the respect and affection they wish to receive in return, for example paying compliments (e.g., Harry), and by sharing the scarce resources they have such as sweets (e.g., Annie). This adheres to Nolan's (2006) senses of 'Belonging' and 'Continuity' (see figure 2, Chapter 1) that are enhanced through building relationships:

**Extract (c) 9: Harry NURSING HOME1 R1 L305-L307**

**Harry** y'see I like to talk to people like that (**paying compliments**) it makes 'em makes 'em feel better (.) makes 'em feel like people are looking up to them 'n' (.) not down (.) I respect other people's feelings (.) always have done

**Extract (c) 10: Annie NURSING HOME3 L529-L537**

**Annie:** yes (.) oh (2) oh yes (.) heh heh heh heh (.) mi Roses tin (.) aye they came (.) they came at Christmas wi that (.) full o' full o' chocolates (.) Roses chocolates (.) when I looked in it were empty heh heh heh heh heh heh

I heh heh heh heh (.) how did that happen then?

**Annie:** but I don't bother (.) no I don't bother

I oh just (.) you let the carers have some yeah

**Annie:** yeah (3)

I is it empty now (.) is it empty then?

**Annie:** I think there's one or two sweets in heh heh

**Summary of Theme 1:** Residents expressed a sense of obligation to give in return for care received. However, residents' ability to give was compromised where they were: resistant/unable to change their behaviour; they felt unable to interact due to dispositional differences; or they lacked the physical resources (e.g., small gifts such as sweets) to gain the favour of nursing care staff. Resources available to residents in the transition into nursing home life is attended to further in theme 3.2.

## Theme 2: Journey into the Nursing Home Community

In Theme 1 ('Constructions of care') I presented residents' perceptions of good and poor care, the social and contextual influences that impact on the delivery of such care, and how residents positioned themselves as deserving of care. In Theme 2 ('Journey into the Nursing Home Community') I present findings about residents' journey from their former life as active participants in wider society to their current role as residents in the nursing home community. This includes the reasons for and how involved residents felt they were in this journey, and the strategies adopted by residents to accept and adapt to this significant change. There are two sub-themes.

### ***Sub-theme 2.1 Blame and the aging body***

In sub-theme 2.1 ('Blame and the aging body'), I present the reasons that led to residents to enter the nursing home and how involved residents felt they were in the decision to do so. I also outline how residents validated their loved ones' failure to care for them in the community through talk of self-blame, and as being a burden on others.

#### *2.1a) Reasons for and involvement in the decision to enter Nursing Home care*

Residents' descriptions of reasons for their journey into care, and if they were involved in the decision to enter care are summarised in table 9. When talking about their reason for entering nursing home care six residents mentioned having fallen, six had compromised mobility, five cited a specific medical condition, three described frailty, three spoke of their spouse or care-giver becoming ill or dying, and three cited safety or isolation. Although physical impairments were cited most, psychosocial reasons for requiring nursing home care were also indicated.

**Table 9: Residents' reasons for entering the NH**

<u>Pseudo nym</u>	NH	Reason for entering NH						Decision to enter NH		
		Fall	Immobility	Loss or illness of another	Medical Condition	Frailty	Safety or Isolation	Own	Joint	Another
Fred	NH1 R1	Yes				Yes			Family	
Harry	NH1 R2					Yes			HP's	
Jessy	NH1 R3			Husband			Yes		Family	
Betty	NH1 R4				COPD					Family
Molly	NH1 R5		Yes	Husband			Yes	Yes		
Doris	NH1 R6	Yes							HP's Family	
Pat	NH2 R1	Yes						Yes		
Mary	NH2 R4		Yes		Stroke		Yes			Family
Hilda	NH3 R2		Yes						Family	
Annie	NH3 R3	Yes	Yes		Alzheimers					"They"
Kath	NH3 R4	Yes							Family	
Shirley	NH3 R5		Yes		Incontinence			Yes		
Vera	NH3 R6		Yes	Brother				Yes		
Nancy	NH3 R7	Yes			Stroke	Yes			Family	

When talking about who made the decision to opt for nursing home care, four out of fourteen residents said it was their own decision; seven suggested it was a joint decision (between them and their family, informed by Health



Professionals); and three said the choice was not theirs. Although 11 out of 14 residents were involved in the decision to move into nursing home care, the wishes of 3 residents (equivalent to 20%) were not honoured. This supports that discrimination in the provision of Health and Social Care services to enable older people to remain in their own homes (e.g., Equality and Equal Rights Commission, 2011) may still exist despite the ability and desire of older people to be involved in decisions about their care: including those with impaired mental capacity (e.g., Hubbard et al, 2003; Brooker, 2004; Carpenter et. al., 2007; and Gallagher 2017). It has also been found that residents who were reluctant to move into the long-term care may be at greater risk of poorer health, moral, and functioning on admission (Sterns, 2007).

Where family were cited as being involved in the decision all were residents' daughter(s). Where another person made the decision, one resident (Annie) did not specify who and referred instead to "they": I attribute this to the fact that Annie experienced Alzheimers Disease, which would make it difficult for her to recall such details.

#### *2.1 b) Perceived burden*

When describing their journey into nursing home care residents usually avoided criticising family and friends for not caring for them in their own homes or in the wider community. Instead, residents positioned themselves as not wanting to be a burden to family and friends, and often cited this as a reason for them choosing nursing home care. This supports findings that nursing home residents at the end of life wanted to feel that they were not a burden, as well as feeling a sense that they had achieved in life, and had social support (Pleschberger, 2007).

As seen (in table 9) six out of fourteen residents had been in hospital following a fall, and during discharge arrangements only two (Pat and Fred) had been given the option to be cared for in the wider community by their loved ones. Typically, both positioned themselves as having chosen nursing home care to avoid being a burden on their daughters' existing socioeconomic obligations: Pat because of her daughters work responsibilities (extract 1), and Fred to avoid disrupting domestic harmony (extract 2). The fact Pat's daughter has work responsibilities supports findings that in the UK the wage differentials between other countries result in migrant care workers providing 24 hour care so that UK citizens can continue to work for financial reasons, or choose to work rather than care for older relatives (Betio et al., 2006).

#### **Extract 1**

**Pat NURSING HOME2 R1 L93-L97** I had somebody there (in hospital) said to me (.) that er (.) I'd be going home (.) well I'd nobody to look after me (.) (**daughter's name**) said "come and live" that's my daughter (.) "come and live with us" (.) I said "I'm not (.) I've had a good life and I'm not going to spoil yours" (.) and she worked at the bank (.) she wasn't a (**inaudible**) she was (.) I don't know (.) her status (.) but she was assistant to whoever was in charge at that time

#### **Extract 2**

**Fred NURSING HOME1 R1 L635:** I don't want to live with them (**daughters**) no I don't because I think that er, I think I don't want 'em to er, have any difficulty with their husbands or anything like that y'know what I mean?

One resident, Shirley, was already being cared for at home by her daughter and chose nursing home care as she felt she was a burden on her daughter who had been her care-giver for thirty years:

#### **Shirley NURSING HOME3 R5L116-L139**

**Int:** can you tell me about how you came to come in (.) and what the circumstances and everything

**Shirley:** well the circumstances (.) I was pooing all over the place

**Int:** yeah

**Shirley:** and my daughter (1) erm (1) got fed up of it y' know (.) and (.) I don't mean I was pooing all the time

**Int:** no

**Shirley:** but when I were it weren't very nice (1) an erm I thought to myself

**Int:** [you were living with your daughter then were yer?

**Shirley:** yeah (.) yeah I lived with my daughter and my grandson (.) er (2) I thought this can't go on y' know (1) it's getting us both down (.) so I said to her "would you object to me going into a care home?" ... she said "no" at first (.) and then when I explained that (.) she's had (thirty) years looking after mi (1) it's about time she had a bit of freedom herself (1) and er (.) thing is (.) she said like (.) erm (3) "would you be happy would yer?" y' know I said "well I don't know" but I said "I'll try it"

When residents acknowledged they were no longer able to manage to live in their home even with support, they justified their relatives' failure to meet their care needs in the community by again positioning themselves as an unreasonable burden on their loved ones. In contrast, where no family support was offered but residents believed they could still live in the community with some support from family and/or other agencies (i.e., Betty and Mary), residents did not justify their relative's failure to support their care preferences. Instead, Betty and Mary talked of their family justifying nursing home care as necessary by expressing concern for the resident's safety and isolation.

#### **Extract 1 Betty NURSING HOME1 R4 L7-L11**

**Int:** what em led you to coming in the home in the first place?

**Betty:** my daughter thought I wasn't managing very well (3) but I think I'm (.) I think I could have done (1) anyway (.) house is sold (.) it's gone (.) house is gone (.) and now I'm here (3)

**Int:** but you thought you could have managed?

**Betty:** well I think I could (2) I'd got this oxygen piped in the house (.) I'd got stair lift (1) so

## **Extract 2: Mary NURSING HOME2 R4 L7-L11 and L401-L417**

**Mary- L7-L11:** I'd been looking after mi husband and he'd just gone into hospital an' while he were in hospital (.) I had mi stroke (1) well mi daughter were working and she'd got a mortgage so she couldn't give it up (.) so they brought me in here (.) after I came out of hospital (1) ..

### **L401-L417**

**Int:** so you said it's frustrating is the way (.) I get the impression it's frustrating that (.) you'd like to be able to manage at home (.) if you could

**Mary:** yeah I would yeah (2) but mi daughter said if I were at home I'd never see anybody (.) I'd have a carer but she says you'd never see anybody at all so you're better off in here (1) where you can talk to people if you want an'

**Int:** hmmm (.) and do you think?

**Mary:** [I suppose she's got a point

**Int:** yeah (2) why was there a possibility that you could've managed at home if you'd got support?

**Mary:** well I thought I could have done

The findings presented in 2.1a) and b) indicate that residents portray their decision to enter nursing home care as either: their own or out of their hands; to avoid being a burden; due to concerns for their own safety; or due to feeling isolated. Where residents felt they could still manage at home and hadn't chosen nursing home living, they suggested that relatives justified not supporting their preferences due to safety concerns, and resident's isolation.

### *2.1c) Blame: loss, ageing and illness*

Previously outlined (1.2b 'conditional care-giving'), residents positioned their receipt of care as conditional upon them being deserving, and upon them giving something in return. To further re-enforce their credibility to receive care residents anchored their need to enter the nursing home as beyond their control and cemented this through narratives of loss associated with ageing and illness. This positioning is consistent with previous findings (e.g., Jolanki, 2004; and Laz, 2003), including findings that the nursing home was a prevalent discursive anchor

for residents' conceptions of ageing that were objectified through reference to their own failing body (Gubrium et al., 1999). In times of illness such rhetorical devices are used to position the self as blameless for the illness in order to remove guilt (Murray, 1997).

**Loss due to ageing:** Here are some examples of how residents talk served to attribute their increased dependence on others for care as being due to ageing:

**Harry: NURSING HOME1 R2 L390-394**

**Int:** it's got on that (.) it's raised a bit isn't it (**referring to photo 6, image of raised seat on the toilet**) what's that for?

**Harry:** oh that's an extra (.) that's an extension that y'see (.) the thing because we're getting old (.) we have ter we need something a bit higher to sit on

**Photograph 6: Photo-elicitation photograph of a raised toilet seat from the interview with Harry|**



**Jessy: NURSING HOME1 R3 L221-222:** mi bit of knitting (.) which is beyond mi now it's got (.) that I can't use my fingers (1) er (.) well I'm rapidly going downhill (.) I know it

**Betty: NURSING HOME2 R4 L94-96** oh yes I don't regret it (**entering the nursing home**) at all because I know full well (.) I couldn't er (.) I couldn't 've done the work (.) I mean I know I'm getting I'm getting more unsteady now (.) this like I've noticed it this last two or three week (.) cos I mean as I say I shall be ninety one on heh (.) (**states birthday**) so that's not far off is it

Residents also referred to old age to blame for the loss of capacity of others: for example, here Hilda refers to the loss of physical capacity of a fellow resident as being due to old age:

**Hida: NURSING HOME3 R2 L445-L447:** and (name of another female resident) has been very ill you know (1) ... but (.) she's still poorly (1) course she's ninety (.) ninety one (1) it's a big age int it?

Whether referring to themselves or others, loss of capacity was positioned as a normal and inevitable part of ageing that was beyond residents' control.

**Loss due to illness:** In a similar way to ageing, residents referred to their own illness or that of others as the reason for needing nursing home care, and also positioned this as beyond their control:

**Mary: NURSING HOME2 R4 L9** ..I had mi stroke (1) well mi daughter were working and she'd got a mortgage so she couldn't give it up (.) so they brought me in here (.) after I came out of hospital (1)

In some cases, decline in the health of others was the reason residents needed to receive nursing home care. For Vera it was the sudden death of her primary carer, and for Jessy it was the decline in health of her husband who now required nursing care as well as her own need for respite care.

**Vera: NURSING HOME3 R6 L5-L8** well er (.) how it was (2) mi (1) mi brother died very suddenly (3) he (2) he went to work one day and he (.) and he died (1) and so we had to (.) family had to get together and I says (.) well I need more looking after than (2) you you lot do (.) so I says er (.) "I'll go into a nursing home (.) and I'll live there like y' know

**Jessy: NURSING HOME1 R3 L173 – L179**

**Jessy:** and they (health and social care) suggested that we had that we went into care (1) for respite for me

**Int:** yeah

**Jessy:** so (3) they they agreed (.) mi daughter and son (1) and er (.) we both went into ... (name of residential care home) ... but the thing was (.) he needed nursing (1) there was no nursing there (.) so (1) they found us another one

This sub-theme suggests residents aim to portray the decision to enter nursing home care as due to a loss of capacity beyond their own control, and as one that is an inevitable result of ageing and illness.

## ***Sub-theme 2.2 Justification for receiving care***

In this sub-theme (2.2), I present how residents justified to themselves and others that they were deserving of receiving nursing home care by positioning themselves as uncomplaining and morally upstanding citizens. Similar although subtly different to Theme 2.1, here residents' accounts depict care as something that is given to those who are worthy and deserving, and that they met these criteria. Residents supported this by reference to their own morals, values, stoic attitude and approach to life, and through downward comparison to other (younger) generations. This is similar to the accounts of nursing home staff participants (see Study 2, Chapter 4) who also used downward social comparisons to retain a sense of positive self-identity in their role as care giver: consistent with Tajfel's (1979) integrative theory of intergroup conflict.

### ***2.2 a) Moral high ground***

All residents positioned their past contributions to society as being of value. Contributions cited included having had a long marriage (e.g. Jessie); positively carrying on despite adversity (e.g. Hilda); and serving in the armed forces (e.g. Harry).

In this example Jessy states that she and her husband had been together since being sixteen. They had worked hard but were happy:

**Jessy NURSING HOME1 R3 L271 – L 272** it is a long time (.) 'n' then we were married for seventy-two years (.) no sixty-six and half years (.) seventy-two is since we were married (2) yeah (.) we had a hard life (.) but it was happy.

Here, Hilda's talk of enduring her own life challenges without complaint is anchored and normalised through social comparison to others that have experienced and conquered serious illness:



**Hilda: NURSING HOME3 R2 L304-L305** but a friend of mine she's had er (.) breast cancer and they've cured her (1) yeah (6) yes I've had mi ups and downs (.) but I carry on y' know

In contrast, Mary has used her time in the nursing home to reflect on her life and suggests she would have benefitted from being less stoic by instead asking for help, a behaviour that is atypical of all resident participants.

**Mary: NURSING HOME2 R4 L312-L333** being in here (.) it's given me space (2) to (.) re-assess what I've done in the past (2) and to (4) not wish I could do it again but (7) this sounds so hackneyed (2) I would do things differently ...L339 -L341 and if I'd responded differently to a number of situations (5) it would have been different (5) and there were several people (.) I could have asked for help (.) before all this (.) and I didn't (.) I just batted along on my own

Commitment to family and a strong work ethic was evident in the accounts of most residents, and a long marriage and enduring austerity were portrayed as having lived a happy and virtuous life.

Additionally, residents were found to draw upon the difference in generations to make comparisons between their sense of duty, morals and values, and those of young people today. Some (e.g., extract 1 Harry) expressed a sense that the contribution of their generation was forgotten or undervalued, and that respect for elders was no longer upheld. This is of concern as theories and models of care for older people highlight that being valued and respected is integral to maintaining dignity and personhood e.g., Gallagher's (2017) ENACT Project supporting care-home specific ways to deliver dignified care and a sense of being valued; Kitwood's (1997) 'positive person work'; Mc Cormack's 'care-processes (2006); and Nolan's (2006) senses of 'significance', 'achievement' and 'purpose'.

**Harry NURSING HOME1 R2 L146-155**

**Harry: THAT'S WHAT ANNOYS ME ABOUT TODAY** (.) they don't teach anything about it at school (.) as far as I'm aware (1)

**Int:** the war?

**Harry:** during the war (.) cos it lasted (1) best part of five years it went on (.) and it was in the first stage it were really tough going (.) cos there was only England and (.) what (**inaudible**) come back (.) cos America hadn't come into it (.) then (.) we had the Halifax Bomber (.) that was a four engine (.) the Wellington Bomber (.) was a two engine (.) you remember all these things y'know

**Int:** yeah (.) y' know it was a hard time

**Harry:** it was a terrible time (.) very terrible (.) but they don't want to know about it (.) I've tried talking to young people but (.) no (.) they're more concerned with booze and drugs

Residents also drew on a lifetime of experience to position themselves as being more tolerant and understanding than those younger than them: this comparison also included nursing home staff despite their knowledge and training as care workers. For example, Nancy compared her present situation, of having to cope with one nursing home carer's indiscreet behaviour, to dealing with the bad behaviour of children she used to teach:

### **Nancy NURSING HOME3 R7 L226-L245**

**Nancy:** the staff on the whole (.) the staff are very very discreet (1) I've grumbled to some of them about (.) her (**carer her daughter complained about officially**) and (2) I didn't realise until a month or two ago (9.0) that she irritates the staff as much as she irritates me

**Int:** oh right (1)

**Nancy:** but I wish she weren't here (.) (**inaudible**)

**Int:** hmmm (7)

**Nancy:** she tends to see the (.) the vulgar side of things (.) and tends to tell jokes

**Int:** right (12)

**Nancy:** I suppose in a way (3) I've handled this before (2) as a teacher (1) used to teach in upper schools in (**name of town**) so I was teaching from thirteen onwards (3) to a certain extent (1) I've learned over the years (1) to (1) not be startled by bad behaviour

As we can see from Nancy's account, some formal care-givers were portrayed treating residents disrespectfully despite residents' previous autonomy

and contributions to wider society. Staff failing to maintain residents' dignity supports previous findings that poor communication by health professionals is common, particularly with older people and people with dementia (e.g., Adelman et. al., 1991; Crossley, 2010; Crotty, 1985; Davies et. al., 2007; Department of Health [DOH], 2013). Such disrespect for residents by staff also contravenes all aforementioned theories and models of care for older people. Regardless of being treated disrespectfully Nancy retains a positive attitude to young people, which may be attributed to her job role that involved working closely with children.

Other residents also talked positively about younger people, but this was usually portrayals of their own children and grand-children. Harry, Molly and Doris were the only residents that didn't have children, and of these only Harry and Doris talked to me about younger people: Harry made negative comments about the attitudes of younger people in general, whereas Doris talked fondly of caring for children in her job role. Overall, analysis of present residents' interviews suggests a positive and tolerant outlook towards younger people, especially where residents previously worked closely with children, or were parents. Considering all care staff were younger than residents themselves, residents' tolerance may provide a buffer in their relationship with care staff, especially when staff fail to treat residents with respect.

### *2.2b) Stoic or be damned*

All residents talk reflected that the personal attributes of a deserving care-recipient included having stoic attitude reflected through unselfish hard work (e.g. Annie's, Jessy's, and Harry's extracts), and passive, uncomplaining acceptance (e.g. Mary's extract). Even Annie who experienced Alzheimer's remembered and

talked of a strong work ethic and enduring poverty as a child, which was something that was deeply embodied in her psyche:

**Annie NURSING HOME3 R4 L302:** and mi dad he used to mend his own shoes (.) we had to do we were that poor (.) he used to have ter (.) mend his (1) shoes

Typical of resident's stories, here Jessy describes how she worked unselfishly to ensure her children received a good education:

**Jessy NURSING HOME1 R3 - L1341 – L134:** our rent at that time it was erm (2) ooh (2) I can't remember now but (2) I know I used to pay it monthly because when I was working I only worked part time just to keep my daughters at school (.) y' know (.) and er all three kids passed the 11+ as it was then (.) and went to Grammar School (.) and that's what I worked for.

In the absence of children, Harry unselfishly served for his country in the services that he considered to be his extended family. Harry never collected the medals he was awarded, demonstrating his unselfish and modest outlook:

**Harry P2NURSING HOME1 L451-454**

**Harry:** I never went (.) I never (.) I should have got medals but I never bothered

**Int:** that's your stripes from yer (.) uniform

**Harry:** yeah (.) but er (.1) aye (.) I'd forgot all about them (2) some years service y' know (2) but it's like a big family in a way y' know (.) your all in together (.) you protect each other

Here Mary talks of resigning herself to accepting the fact she is in the nursing home even though she felt she could have managed at home with support:

**Mary NURSING HOME2 R4 L417:** I suppose you've got to put up with what you've got don't yer (.) can't do nowt about it (.) no good making a fuss

In addition, residents felt that other residents should retain a stoic attitude within the nursing home. For example, prompted by a photo-elicitation photograph (no 7) of signage on her bedroom door Jessy was prompted to talk about a new resident that she believed was breaking the nursing home's rule on smoking, and implied that the intelligent thing is to adhere to the rules of the nursing home community:

**Jessy NURSING HOME1 P3 L26-L41:**

**Jessy:** oooh yes (.) definitely (1) yes (2) I'm glad you've got that on (photograph) er there's a notice (.) on one o' t' doors

**Int:** about smoking in rooms

**Jessy:** yeah (1) I think she she must have been (1) smoking in her room

**Int:** who?

**Jessy:** just on the corridor (1) she was a new lady (1) ... and I didn't know she smoked (1) and I saw I sat outside one day (3) and she was smokin' (2) an' I thought (1) oh I didn't know she smoked (.) and then I saw that notice on her door

**Int:** so how long has that notice been on your door (referring to photograph)

**Jessy:** all the time I've been here

**Int:** oh right (.) ok so

**Jessy:** the one I'm talking about it's on the outside of the door

**Int:** oh right

**Jessy:** so that makes me think that she's she was caught smoking in her room (1) they know the rules (1) and she's an intelligent woman

Photograph 7: Photo-elicitation photograph of no smoking sign on resident's bedroom door from the interview with Jessy



This sub-theme demonstrates residents' passive acceptance of their need for care, and compliance to the rules of the nursing home institution. This and findings of the present observations conducted in study 1 (Chapter 3), suggest the biomedical model of care exists in participating nursing homes. It also suggests that in accordance with Crossley (2010), the hegemony of the biomedical model leads to objectification of residents, and excludes the contextual, social, and relational factors deemed necessary to maintain personhood, and dignity conserving care (e.g., Brown, 2008; Gallagher, 2017; Kitwood, 1997; McCormack, 2004: 2006; Nolan, 2001:2004:2006; Ryan, 2008).

### Theme 3: Adjusting to Nursing Home Living

This theme builds on previous descriptions relating to the reasons why residents entered the nursing home (see theme 2.1) and explores the relationship between how these decisions were made and the degree of acceptance and adjustment to nursing home living experienced by residents. Specifically, qualitative interviews offered insight into how well residents had adjusted to the nursing home community, and residents' degree of satisfaction with nursing home living. There are two sub-themes in this chapter. First, sub-theme 3.1 ('Characteristics') outlines the extent to which residents felt they had control over the decision to enter the nursing home and how accepting they were of their new role as a nursing home resident. Second, sub-theme 3.2 ('Transforming self-identity') represents what helped or hindered residents' ability to adjust to the nursing home community.

#### ***Sub-theme 3.1: Characteristics***

Here I present residents' self-positioning that was found to fall broadly into three characteristics: '**Control**'; '**Acceptance**'; and '**Belonging**'. The first characteristic, 'Control' (touched on briefly in theme 2.1), reflects residents' perceived sense of involvement they had in the decision to live in the nursing home: ranging from either 'autonomous' to 'involved' to 'excluded'. The second characteristic, 'Acceptance', outlines how compliant with nursing home life residents were: ranging from 'accepting' to 'resigned' to 'resistant'. The third characteristic, 'Belonging', reflects the extent to which residents felt part of the nursing home community: ranging from 'integrated' to 'participating' to 'disenfranchised'.

Each resident's characteristics are presented in table 10 and are based on the most dominant discourse in each resident's interview. However, there was some conflict in most residents' narrative in relation to each characteristic: therefore, to ensure that my interpretation reflects as accurately as possible each individual resident's perspectives I compared each interview transcript with corresponding detailed field notes that I wrote immediately after conducting the interviews.

### 3.1a) *Control*

In Characteristic 1 ('Control') I have positioned residents into each of three levels of control based on their talk about the decision to enter the nursing home. The four residents (Molly, Vera, Pat, and Shirley) that made the decision to enter the nursing home themselves were grouped as '**Autonomous**', for example:

**Molly NURSING HOME1 R5 L85..** they were leaving it to me cos I was the one that (.) that had got to move

**Vera: NURSING HOME3 R6 L5-L8** well er (.) how it was (2) mi (1) mi brother died very suddenly .. so I says er (.) "I'll go into a nursing home (.) and I'll live there" like y' know

**Pat: NURSING HOME2 R1 L95-L95** (daughters' name) said "come and live with us" (.) I said "I'm not (.) I've had a good life and I'm not going to spoil yours"

**Shirley NURSING HOME3 R5 L125-L127:** I lived with my daughter and my grandson (.) er (2) I thought this can't go on y' know (1) it's getting us both down (.) so I said to her "would you object to me going into a care home?"

The seven residents (Fred, Harry, Jessy, Doris, Hilda, Kath, and Nancy) that made the decision to live in the nursing home jointly with others such as Health and Social Care services or family, were grouped as '**Involved**', for example:

**Jessy: NURSING HOME1 R3 L173 & L201:** and they (health and social care) suggested that we (**Jessy and her husband**) went into care (1) for respite for me ... (.) we knew we'd got to come in somewhere .. **L201** I says "ooh it's lovely int it?" (.) "do you think mi dad'll like it?" (.) and he said "yes (.) I understand" (.) and he was quite happy here



**Doris: L92-97 & L129-130:** I fell one morning..(.) and it was from then that (2) so then I mean (.) I don't think I should ever have got (.) **I** shouldn't go back to (.) to do by myself ...**L129-L130 ..they** (friends) just brought me in (1) showed me the room 'n' (1) that was it an' I came

Finally, the three residents (Annie, Mary, and Betty) who gave the impression that others made the decision for them to live in the nursing home without their involvement were grouped as '**Excluded**': this includes Annie who experienced Alzheimers and whose family had Lasting Power of Attorney (LPA) to make decisions on her behalf, and in her best interest.

**Annie: NURSING HOME3 R3 L22:** I couldn't tell you (2) I can't remember how I come to live here

**Mary: NURSING HOME2 R4 L9** ..I had mi stroke (1) well mi daughter were working and she'd got a mortgage so she couldn't give it up (.) so **they** brought me in here (.) after I came out of hospital

**Betty NURSING HOME1 R4 L8-9** my daughter thought I wasn't managing very well (3) but I think I'm (.) I think I could have done (1) anyway (.) house is sold (.) it's gone (.) house is gone (.) and now I'm here

Table 11 maps each individual resident's Characteristics 1, 2 and 3

('Control', 'Acceptance', and 'Belonging'). Findings mapped here suggest that regardless of which nursing home the resident lived in, the amount of 'Control' that residents had over the decision to enter the nursing home (Characteristic 1) did not seem to influence the extent to which the resident either 'accepted' nursing home living (Characteristic 2), or subsequently felt they 'belonged' to the nursing home community (Characteristic 3).

**Table 10:  
Residents'  
Characteristic  
1: Control**

		Autonomous (A)		Involved (I)		Excluded (E)	
		Char 2 Accepting	Char 3 Belonging	Char 2 Accepting	Char 3 Belonging	Char 2 Accepting	Char 3 Belonging
		A) Accepting B) Resigned C) Resistant	A) Integrated B) Participating C) Disenfranchised	A) Accepting B) Resigned C) Resistant	A) Integrated B) Participating C) Disenfranchised	A) Accepting B) Resigned C) Resistant	A) Integrated B) Participating C) Disenfranchised
Pseudonym	No wk						
Fred: nursing home1 R1	24			I2B) Resigned	I3B) Participating		
Harry: nursing home1 R2	30			I2A) Accepting	I3A) Integrated		
Jessy: nursing home1 R3	78			I2A) Accepting	I3A) Integrated		
Betty: nursing home1 R4	10					E2B) Resigned / E2C) Resistant	E3C) Disenfranchised
Molly: nursing home1 R5	25	A2A) Accepting	A3A) Integrated				
Doris: nursing home1 R6	13			I2B) Resigned	I3B) Participating		
Pat: nursing home2 R1	84	A2B) Resigned	A3B) Participating				
Mary: nursing home2 R4	72					E2B) Resigned	E3A) Integrated
Hilda: nursing home3 R2	26			I2B) Resigned	I3B) Integrated		
Annie: nursing home3 R3	12					E2A) Accepting	E3B) Participating
Kath: nursing home3 R4	50			I2A) Accepting	I3A) Integrated		
Shirley: nursing home3 R5	3	A2B) Resigned / A2C) Resistant	A3C) Disenfranchised				
Vera: nursing home3 R6	18	A2A) Accepting	A3A) Integrated				
Nancy: nursing home3 R7	18			I2B) Resigned	I3B) Participating/ I3C) Disenfranchised		

**Table 11: Residents' characteristics 'Control' 'Accepting' and 'Belonging'**

NH 1 NH 2 NH 3			
Characteristic 1 CONTROL	Characteristic 2 ACCEPTING	Resident & No Weeks in NH	Characteristic 3 BELONGING
A) Autonomous	A) Accepting	MOLLY 25 VERA 18	A) Integrated
	B) Resigned	PAT 84	B) Participating
	C) Resistant	SHIRLEY 3	C) Disenfranchised
B) Involved	A) Accepting	HARRY 30 JESSY 78 KATH 50	A) Integrated
	B) Resigned	FRED 24 DORIS 13 HILDA 26 NANCY 18	B) Participating
	C) Resistant		C) Disenfranchised
C) Excluded	A) Accepting	ANNIE 12	A) Integrated
	B) Resigned	MARY 72	B) Participating
	C) Resistant	BETTY 10	C) Disenfranchised

### *3.1b) Accepting, Belonging and Duration*

As indicated in table 11 and based on interview dialogue, each resident was found to fall into one of three levels in Characteristic 2 that reflected how 'accepting' residents were of nursing home living: either 'resistant', 'resigned', or 'accepting'. In two of the interviews with residents, their comments suggest they sat between these levels of 'acceptance' i.e., Betty's and Shirley's comments were both resistant and resigned. In turn the level of 'acceptance' of nursing home living reflected in residents' talk was found to relate to the level of 'belonging' (Characteristic 3) to the nursing home community expressed by residents: either 'disenfranchised'; 'participating'; or 'integrated'.

First, my analysis of resident's qualitative descriptions suggests those that were more 'Resistant' to nursing home living were more likely to talk of being 'Disenfranchised'; second, residents who's talk was more 'Resigned' were more likely to talk of 'Participating'; and third, residents that talked of being more 'Accepting' were more likely talk of being 'Integrated'. Only one resident's talk sat between these levels of 'belonging' i.e., Nancy's talk was both disenfranchised and participating. The length of time residents had lived in the nursing home also seemed to influence their sense of belonging to the nursing home community. Residents living there less than 12 weeks were more likely to be 'disenfranchised'; between 13 and 25 weeks were more likely to be 'participating'; and over 26 weeks more likely to be 'integrated'.

#### *Level of accepting: Resistant*

The narrative of the two residents whose acceptance of nursing home living fell between resigned and resistant (i.e., Shirley and Betty) conveyed that they predominantly felt 'disenfranchised' from the nursing home community. Unlike all other participants, Shirley and Betty had each lived in the nursing home for less

than 12 weeks: Shirley in nursing home number three for 3 weeks, and Betty in nursing home number one for 10 weeks. For Shirley and Betty feeling disenfranchised was articulated through them experiencing conflict. This included being accused by nursing home staff of not complying with (either actively resisting, or simply not knowing) the nursing home rules (specifically the rules on smoking), which they said made them feel angry and lost:

**Betty NURSING HOME1R4 L52-L53** they don't take your word for it...it makes me feel angry... I don't break rules (2) they've a few too many here (2)

**Shirley NURSING HOME3 R5 L75 – L83** well (1) how do I feel? (.) at the moment (.) I feel lost (.) I feel (1) erm (.) nothing's going right (.) then when they said we can't go for a cigarette (1) only on the front ..an' I do understand that but (.) I think well (.) I've mi rights as well y' know

Additionally, the two residents that still predominantly 'resisted' nursing home living talked about feeling: un-supported by staff (**extract 1 Shirley**) and relatives (**extract 2 Betty**); unheard and disbelieved by staff (**extract 3 Betty**) and relatives (**extract 4 Shirley**); and bullied by staff (**extract 5 Shirley** and **extract 6 Betty**).

**Extract 1 Shirley NURSING HOME3 P5 L95-L97:** well if you've got a relation (.) or one of the staff's free (.) if they're free (.) I mean some'll say "aye I'll take yer down in ten minutes" or "oooh I can't" y' know (.) just depends how they feel (.) an' er (.) I don't know where I stand

**Extract 2 Betty NURSING HOME1 R4 L190-L192:** no they (**daughter and grandson**) don't come (.) some people get visitors two or three times a week .. but I don't (.) cos I 'ant got nobody

**Extract 3 Betty NURSING HOME1 R4 L40-L41:**...my idea of care is one person listening to another person (2) .. cos there isn't that (.) but I I keep out of it (.) I'm havin' nothin' to do with it (5) I expected more..freedom

**Extract 4 Shirley NURSING HOME3 P5 L190-L193:** mi daughter said to me the other day (.) "mum (.) you're confused again" (.) and I say "I'm not confused (.) I'm trying to express miself" y' know "I'm telling you what's wrong (.) "no your moaning" (.) an' I think (.) am I? (2) but I try and get it out and she'll say "oh we'll have to go"

**Extract 5 Shirley NURSING HOME3 L 243-247:** I went three days without a cigarette and they (**nursing home staff**) were saying "oh you've done

well you've give up cigarettes (.) I said "I haven't! (.) it's only cos I'm poorly" (.) but "oh you'll be alright you'll be alright giving up cigarettes" (.) an' trying to make your mind up for yer (.) I know what they're trying to do (.) give up altogether (.) but I will never (.) give up cigarettes because I like 'em too much

**Extract 6 Betty NURSING HOME1 R4 L243-L244:** I don't know who to trust (4) coming up in the lift (.) a gang of girls going down (.) all that work up here (.) they never said a word to me .. never said hello

*Level of accepting: resigned*

Of the six residents whose narrative positioned them as 'resigned' to nursing home living, none talked of feeling completely 'disenfranchised'. Nancy was now resigned to her situation, participated in the community more, and had been in the nursing home for longer than Shirley and Nancy (who were resigned but felt disenfranchised). However, Nancy also talked of feeling 'disenfranchised' initially: due to being bullied by staff and feeling unable to complain to management. This suggests feeling disenfranchised from the nursing home community is more prominent in the first weeks/months after moving in:

**Nancy NURSING HOME3 R7 L140 – L147** she never spoke (3) and the first morning (3) I was getting dressed (2) I was being dressed (2) and I had a physical fight (1) with the helper (2) she was forcing me to put a shirt on which I didn't want (1) and I said to her "this is bullying" (2) and I don't know what she said (.) but she was like a tank she didn't stop (5) I couldn't do anything (2) it was (.) I was too much of a new girl (.) to (.) speak to management (2) I think it was great mistake

However, with support from her daughter a formal complaint about being bullied had ensured the accused carer would no longer deliver Nancy's personal care. Of interest is that there was a sharp increase in complaints from staff and relatives about the treatment of older people between February 2011 and June 2012 (BBC News: 23 June, 2012): the same timeframe in which present data was collected. This suggests residents with relatives or those living in nursing homes

where staff are brave enough to speak up are most likely to have their complaints voiced.

A further two of the six 'resigned' residents (Hilda and Mary who lived in different nursing homes for 26 and 72 weeks respectively) talked as if fully 'integrated' in the activities of the nursing home community (e.g., extract 7 Hilda)

**Hilda NURSING HOME3 R2 L140 – L141:** they take us down to er (.) bingo 'n' er (.) different carryings on (.) today it's er horse racing **L145-L147** I enjoy it...I'm quite happy here **L153-L154** people come in an' er they talk to me 'n' we have a good laugh (.) hah hah hah ha heh (.) they all laugh at (.) they all love me heh heh

Although mainly integrated, Mary's social life was recently negatively impacted by the death of a fellow resident and friend **Mary: NURSING HOME2 R4 L388-L390** "*when (name of resident) was alive she were here (.) we used to play cards me and her every day we had some right laughs (.) but there's nobody can do that now y' know (.) they're either asleep or they can't say much*". Mary's account indicates the immediate negative impact this bereavement has had on Mary's mood and social life within the nursing home, which arguably could impair Mary's level of integration in the nursing home community. This may be exacerbated by poor detection and treatment by staff of depression among older nursing home residents, with prevalence between 15-25% in the United Kingdom (McCabe, 2009): this is often due to poor staff attitudes and training in detecting symptoms (Brown; 2003;2004; McCloskey, 2007).

The remaining three of the six residents whose talk suggests they were 'resigned' to nursing home living (i.e., Pat, Fred, and Doris) indicated that they were 'participating' in the nursing home community, but not fully integrated. Analysis of their interviews suggests this may have been due to the relatively self-contained lifestyle of these residents prior to living in the nursing home. For

example, Fred had social skills through work, but as a single parent had little time to socialise and instead had interests he could follow at home, such as watching football on TV. Although Fred was prepared to socialise within the nursing home, he still valued his own company and was only prepared to engage in activities that specifically interested him (see extract 7: Fred):

**Extract 7 Fred NURSING HOME1 R1 L167-L169.** they play bingo don't they I mean I I don't play bingo at all I'm not (1) I I don't want to be stand offish (1) but er (2) I think miself that er (1) I mix with 'em (1) 90 odd percent of 'em y'know

*Level of accepting: accepting*

Of the six residents whose narrative positioned them as more accepting of nursing home living: five (Molly, Vera, Harry, Jessy, and Kath) talked as if they were integrated in the nursing home community, and none talked of feeling disenfranchised. For example, **Vera**: *“you go to where they're doing little exercises, in the afternoon there's some things going on .. they're playing dominos and things like that,. they try to keep you occupied”*). One resident talked of merely participating rather than being fully integrated which may be due to her lack of mental capacity i.e., **Annie**: *“I just have mi meals and then they take me ... I like to take mi meals somewhere and (staff) fetch mi back”*). This finding suggests that accepting their situation and engaging in organised activities may facilitate residents' integration into the nursing home community, regardless of their control over the decision to enter the nursing home. Such problem-focused rather than emotional-focused coping strategies have been found to improve older adults' well-being (Galiana, Tomás, Fernández & Oliver, 2020). Additionally, most residents that were both accepting of their situation and integrated into the nursing home community were found to have lived in the nursing home for 25 weeks or more. These findings suggest that residents'



'acceptance' of nursing home living develops over time and occurs most often after living in the nursing home for six months or more. Findings also suggest that 'acceptance' facilitates residents' ability to become a fully integrated member of the nursing home community.

### ***Summary of Sub-theme 3.1***

This theme highlights the reasons for and extent of involvement that residents had in the decision to enter the nursing home. Consistent with existing theory and research (Gubrium et al. 1999; Murray, 2000; Ricoeur, 1979; and Stephens, 2011), residents anchored their need for care as external to them through discourses of loss associated with ageing, a failing body, and bereavement. In this sense residents' inability to control such external forces did not in itself appear to affect their ability to integrate into the nursing home community. Consistent with Nolan's 'Senses Framework (e.g., Brown-Wilson et al, 2012; and Ryan, 2008) residents that were believed by and had good support from their family, nursing home staff, and other residents, felt a greater sense of belonging, which facilitated integration. Regardless of the aforementioned, residents who had lived in the nursing home for more than 3 months seemed more integrated within the nursing home community than newcomers.

In comparison, where residents were ignored, disbelieved by family, nursing home staff or other residents, and/or roughly handled by nursing home staff, they felt resistant to and disenfranchised from the nursing home community. This was especially so if the resident had not accepted the decision to enter the nursing home. This behaviour was reported by current residents as being most prevalent when newly admitted to the nursing home. Previously, such negative attitudes among carers was found to reduce detection and treatment of depression among

residents (McCabe, 2009), especially when combined with a lack of appropriate staff training (that was described in chapter 4, Staff Focus Group). This is of concern as suicide rates are more problematic among nursing home residents that express dissatisfaction with care or treatment (Jongeneelis et al., 2004). Also, mortality rates are highest in the first few months following admission: especially among nursing home residents compared to those in residential or mixed care settings (Forder et al., 2011). Past and present findings highlight the need for nursing homes to have appropriate structures (e.g., relationship focused models of care) and staff training (e.g., bereavement, detection of depression, dignity conserving care) in place to ensure residents' transition into the nursing home community is a smooth one.

### ***Sub-theme 3.2: Transforming Self-identity***

As outlined in theme 3.1 ('Resident characteristics') analysis of qualitative data from resident interviews shows that residents' 'acceptance' of nursing home living was most challenging in the first 17 weeks, and thereafter residents appeared to be more integrated into the nursing home community. This theme explores how residents adapted to their new role as a recipient of nursing home care, and what facilitated or hindered this process. Residents adopted a range of strategies including becoming more passive and compliant; personalising their immediate surroundings; engaging with existing relationships or building new ones; and adopting an identity role that was acceptable to the nursing home community. Resident's success in re-building their self-identity as a nursing home resident was largely dependent upon the resources available to them.

### 3.2a) Finding a Niche

Residents' transition and integration into nursing home life was found to be a complex and difficult path to negotiate. Any resident that was perceived by other residents or nursing home staff as not having the attributes of a deserving care recipient (outlined in theme 2.2b: 'Stoic or be damned') or as resisting the rules of the nursing home community, felt less welcome than residents that were resigned to or/ fully accepted the role of a 'compliant' nursing home resident. Residents that were perceived as breaking the nursing home rules were outlined previously in theme 1.3b: for example, other residents breaching 'no smoking' rules (Molly extract C6). Even after living in the nursing home for 6 months Fred's resistance to nursing home rules regarding personalising his own bedroom space left him feeling alienated by staff (Theme 1.2 b - Fred L 453-L486). Resident's alienation included being ignored and/or disbelieved by nursing home staff and residents.

Other residents that had lived in the nursing home for longer than 12 weeks had also experienced such alienation and bullying when they had first moved into the nursing home: for example, Nancy had resisted a nursing home carer's rough handling of her on her first day (see theme 1.3 b: Nancy L140-147). In response, Nancy had adopted a new strategy of passive resignation to help her cope with her role as a recipient of nursing home care (see L168-188 below). This demonstrates Nancy had self-regulated to the medical and ageist discourses that I found to be embedded within the nursing home community: in accordance with Goffman's (1961) 'total institution'. this is symbolic of Nancy becoming institutionalised, and thus disempowered.

**Nancy NURSING HOME3 R7 L168 and L188** I make myself (.) more passive (2) but not always (8) (I tell myself) it's not so bad .... I let the unpleasantness roll over me

As previously attended to (theme 1.3) the belief and support of her daughter (who had made a formal complaint about Nancy's experience) and Nancy's adoption of resigned and compliant behaviour seemed to have reduced, although not completely eliminated, the tension Nancy now experienced in her relationship with nursing home carers. As previously mentioned, this complaint by Nancy's daughter corroborates a sharp increase in complaints from staff and relatives, with more than 4,300 complaints made about the treatment of older people in care between February 2011 and June 2012 (BBC News: 23 June, 2012). Overall, my analysis (within and between participants' accounts) suggests that residents that had learned and adhered to the rules of the nursing home community were more readily accepted by other residents and nursing home staff. In turn compliance facilitated residents' transition to nursing home living.

### *Disposition*

I noted that residents whose interactions with me during interviews portrayed either a gregarious (e.g., Mary and Hilda) or passive (e.g., Jessy and Molly) nature talked of being more integrated in communal activities. In contrast introverted residents tended to be less involved in nursing home communal activities and either failed to identify any positive relationships and/or experienced negative relationships within the nursing home (e.g., Betty). Based on analysis of qualitative interviews with residents, those that were inherently gregarious appeared best able to boost and re-build their self-identity. As suggested by existing relationship-focused models of care (Brown-Wilson, 2012; McCormack, 2004; Nolan, 2006; & Ryan, 2008), residents achieved this by establishing

numerous relationships with staff, and with other residents and their visitors. Building relationships was facilitated by regularly attending communal and organised activities within the nursing home such as watching TV and dining with other residents and attending social activities such as appointments with the nursing home hairdresser, group games and crafts. Again, this supports findings that problem-focused coping compared to emotional-focused coping promotes wellbeing in older people (Galiana et al., 2020).

Residents who were either less gregarious and/or physically unable to mobilise without help from nursing home staff were more inclined to stay in their own bedrooms and only occasionally engaged in communal activities beyond mealtimes. However, where less exuberant residents had opportunities to engage in problem-focused activities by themselves that were meaningful to them (such as reading, watching TV, or knitting) they portrayed themselves as more accepting of/resigned to nursing home living (e.g., Pat; Doris and Nancy). This problem-focused approach has been found to promote well-being (Galiana, 2020)

Other residents adapted by finding a unique positive role for themselves as active participants in the nursing home community. One resident (Hilda) spoke of being called 'the Queen' by staff and other residents, and had built herself a reputation for always being positive and funny. Kitwood suggests such personal labelling in institutional care is representative of 'malignant social psychology', although others suggest it may provide a positive means of identity construction that helps individuals negotiate an ageing identity and connect with their new social world (Percival, 2000). Some residents that had regular visitors (e.g., Fred; Jessy; Doris; Mary; Hilda; Annie and Kath) were able to retain roles they identified

with from when they lived in the wider community: such as grandmother/grandfather; mother/father; aunt/uncle; or friend. Such roles were reinforced in residents' personal physical environment through memorabilia such as family photographs, ornaments and objects (see table 6: photographs in residents' bedrooms) and also through regular social contact with family and friends. Where residents had infrequent or no visitors, these former roles were harder for residents to retain (e.g., Betty; Pat and Shirley).

Most residents that referred to their present-self positively (such as Hilda) had lived in the nursing home for 24 weeks (6 months) or longer, and appeared to have re-defined their self-identity to include being a member of, and valuable contributor to, the nursing home community: meeting Nolan's (2006) senses of 'belonging', 'continuity', 'purpose', 'achievement' and 'significance'. This finding suggests an adjustment period of at least 6 months is necessary for residents to begin to rebuild their self-identity and adapt to living in the nursing home. Examples of roles residents adopted to regain a sense of self included listening to the carer's troubles and making people laugh (e.g., Hilda); remaining independent (e.g., Fred); being positive and showing gratitude for what they have (e.g., Harry and Molly); and being a friend to other residents (e.g., Mary). Regardless of disposition, if residents were unable to engage in meaningful activities (either due to impairment or because they were made to feel marginalised) they tended to portray themselves as unfulfilled, discontent, and unhappy with nursing home living.

### *3.2b) Resources: Scarce or Otherwise*

#### *Adapting surroundings*

In order to make sense of their situation residents made numerous references to their former contributors to society not only to justify their right to receive care (as outlined in Theme 2.2: Justification for Care Receiving), but also to provide a strong foundation on which to reconstruct their currently depleted sense of self. Residents' construction of their current self-identity was often through negative narratives of old age and incapacity (see theme 2.1c, Blame: loss, aging and illness), which is a way older people reconstruct their self-identity (Jolanki, 2004; and Ricoeur, 1992). Residents adopted a number of strategies to help re-build a more positive self-identity, including improving their immediate surroundings.

An aid to residents adapting to nursing home life (and also their families) was to make their 'personal space' (bedroom) as homely as they could by surrounding themselves with meaningful objects. Examples of some of these items included family photographs, ornaments, pictures, cuddly toys, clothing, furniture and books (see table 6: example photographs in residents' bedrooms). In accordance with Goffman's (1971) idea that objects are 'tie-signs' that represent social bonds, for residents, familiar and sentiment-laden objects served to anchor their present 'dependent-self' to their former 'autonomous-self'. These objects provided a tangible mirror to residents' former-selves that was visible not only to them, but also to others (visitors and staff) within the nursing home community. This served to view residents through a positive lens, thus boosting their self-esteem. I found that residents' belongings were a representation of their personhood and (in accordance with Goffman's 'tie signs') materially facilitated

interactions between them and care-givers and thus promoted relationship enhancing moments. For example, in all interviews I conducted with residents, objects became a focus for residents' stories, and elicited memories and emotions across the spectrum from melancholy to joy.

In addition to anchoring to the past, residents who seemed resigned to or accepting of nursing home living also talked of acquiring objects since living in the nursing home that helped them to adapt to their new surroundings and needs: for example, Jessie's family had bought her a mini-fridge. Of the three residents that portrayed themselves as disenfranchised one hadn't had the opportunity to personalise their bedroom yet (Shirley), and two (Betty and Nancy) were disinclined to do so as they perceived the nursing home as an institution that would never be their home. As depicted by Nancy in the following extract, and in support of action research in care homes (Gallagher, 2017), the fact that residents hadn't invested in the creation of the nursing home meant that acquiring a sense of belonging was even more challenging: especially as the nursing home environment was beset with formal notices portraying the medical and risk-adverse discourses embodied at organisational level, such rules and regulations.

**Nancy NURSING HOME3 R7 L636-L644:** I feel about those notices (.) I'm I'm in an institution (.) so I'm in an institution (.) and never even queried those things (.) on the wall (**rules and notices**).. never thought of it (1) cos I don't feel that this is my home (.) at all (.) this is where I am (.) and this is where I'll stop (3) but I don't care what they do how they arrange it because (3) I don't identify with it .. never feel like home (4) because I haven't created anything

However, for most residents that had been in the nursing home for more than 3 months, having photographs and memorabilia around them in their bedrooms appeared to help them stay connected to their former self-identity as an independent contributor to wider society.



### *Social and Material Resources*

In addition to changing their own behaviour (e.g., becoming more passive) and personalising their environment (i.e., bedroom), what appeared to help residents adjust to living in the nursing home community was the ability to retain existing and/or establish new 'caring' relationships' (as defined in Theme 1: Constructions of Care). I found residents who retained at least some elements of their former self-identity (equivalent to Jacobson's, [2009] 'dignity of self'), appeared more contented with and accepting of their present life in the nursing home community. For example, Doris didn't have any family, but had close connections with friends who visited her or took her to engage in non-nursing home activities each week, such as attending church.

**Doris NURSING HOME1R6 L18-192** well now I can't go out (2) by miself now I mean er (1) I went to I used to go down to chapel (.) to the dinner on Tuesday (.) to church on Sundays but er (.) I can't now (.) **(friend's name)** a gentleman from church he comes and takes me (.) or **(friend's name)** she's got a car (.) but they're all very kind down there y' know they do help me a lot

In addition to having social resources to support interactions with others I found residents that were more integrated into the nursing home community also had access to material resources that helped them maintain some independence. These material resources were both in and outside their own bedroom and provided by themselves or the nursing home. For example, residents, (and especially chair-bound residents such as Pat), used bedside tables that were provided by the nursing home to keep things close to them that they used frequently such as drinks, clocks, glasses, hearing aids, snacks, tissues, and remote controls. Such facilitation is representative of Kitwood's 'positive person work', that has been found to improve the wellbeing and

physical outcomes of older residents (Mitchel, 2015). However, not all basic resources to meet residents' physical care needs were provided by the nursing home, and thus required the resident to pay for services (e.g., physiotherapy for Mary, and chiropody for Fred) or equipment (e.g., a recliner chair for Pat – see below extract). This was prohibitive for some residents without the means to afford or seek out such provision.

**Pat: NURSING HOME2 R1 L222-228**

**Pat:** now I WANT TO GET RID OF IT (.) and I can't tell anyone to get rid of it (.) now I say (.) to the manager here (.) "I could do with a new chair" (.) so she said "whey if you want a new chair you have to buy one" (.) I says "well I'm not buying 'em"

**INT** hmmm

**Pat:** I mean those other green ones (.) everybody nearly everyone's got one excet me because this chair's alright (.) it gets me mad that a bit (1) because (oh I don't know they're) (.) they're classed as (.) what as patients? (.) I don't know (.) well I'm a patient (.) as well heh heh (.)

In addition to having physical resources and services, having the ability to call for help if needed using the nurse call buzzer system also afforded some independence. However, the resident still remained dependent on the care-giver responding swiftly, which was variable and often dictated by rationalised discourses i.e., slower response times by staff were blamed on staff shortages and routine working practices. This has been demonstrated recently where increased staff shortages were found to impact negatively on service delivery (McKenna et. al., 2019).

Again, I found shortage of organisational level resources particularly affected the direct care received by physically immobile residents such as Pat, including basic needs such as being able to look out of the window to break the monotony of the day, or go to the toilet:

### **Pat NURSING HOME2R1 L433-440**

**Pat:** I can't get up (1) to stand (3) er (.) so unless anybody takes me right to the window (.) and nobody's any time (.) they haven't got time (.) they're short of people (1) for this kind of work

**INT:** hmmm (4) does (.) does that (.) affect you in any way? (1)

**Pat:** er (1) it doesn't affect me (1) but erm (.) cos I'm not one of those type of persons (.) er (.) I don't know what to say (1) it affects me say I want to go to the toilet (.) that affects me because they'll say "oh you'll have to hang on" or "it's dinner time" or something like that (.) that affects me(.)

In contrast, the bedrooms of residents that were new to the nursing home and were 'disenfranchised' from its community (i.e., Shirley and Betty), had little evidence of items other than those provided by the nursing home. Shirley, who had chosen to move into the nursing home, considered her bedroom space to be impersonal and spoke of frustrations at not being able to take ownership of her personal space. This does not align with 'positive person work' that requires stimulation, relaxation, creation, and validation for care recipients (Mitchell, 2015). This was again due to rationalised and risk-adverse discourses at organisational level, for example, not being allowed add personal touches to the décor such as a border on the walls and having to wait for the handyman to come to fix her bed and put up her photographs.

**Shirley NURSING HOME3 R5: L683-L686** y' know mi grandson said (.) "I'll put yer a border up" (.) he's bought me a border ...can't put borders up cos they're pulling 'em down **L 726-L730:** the odd man has to put 'em up (pictures .... so I'm waiting (.) he's only t' come up here and do it y' know

In contrast Betty, who did not want to move into the nursing home, lacked the motivation to personalise her space, and didn't feel like it belonged to her.

### **Betty NURSING HOME1 R4 L156-L158**

**Betty:** It's not my sort of picture (.) and it's not my wall

**INT** Would you not rather them take it down?

**Betty:** I'm not bothered

Although Betty and Shirley lived in different nursing homes, they both experienced the same conflict with staff and other residents, and didn't have the support from their family that they had experienced outside the nursing home. Consistent with Kitwood's 'malignant social psychology', this made them feel unheard, alienated, frustrated, uncared for, and for Betty it also made her feel angry that she was paying for a service that she neither wanted or was satisfied with (**Betty:** *"I think I don't want to be here, it makes me angry to think that I pay as well"* L73-L74).

Overall, residents talk depicted a more positive portrayal of their experience of nursing home living where they had regular contact with family and friends or community groups than those residents that did not (e.g., Fred; Doris; Hilda; and Kath). Face to face contact was portrayed to be most desirable, although contact by telephone, letter or via social media were talked about more positively than having no social contact with family and friends (e.g., **Molly:** *" I love writing a letter to such as mi sister .. I take it to the office and then they'll do the posting y'know it is (.) it's really good"* L356-358).

### **Summary of Sub-theme 3.2:**

In theme 3.2 I presented my findings that residents' sense of belonging and their ability to adapt to nursing home living was linked to their how well they were able to understand and adapt to institutional rules and transform their self-identity to that of a passive or active, but always compliant, recipient of care. This transformation was facilitated where residents were able to find and adopt a

suitable 'niche' that was acceptable to other residents and staff (sub theme 3.2a), and where they had access to material and/or social resources (theme 3.2b). The resident's disposition also influenced their level of engagement in the nursing home community with extravert or passive residents generally being more engaged than introverted residents, although this was reconciled where the latter found solace in meaningful solitary activities. Findings also suggest that: environmental discourses depicting the nursing home as an institution rather than a home (medical, legislative and rationalised discourses found at organisational level and presented in Chapter 3); a failure to explain the rules of the nursing home community for new residents; and the absence of relationships with other nursing home residents and staff, impaired resident's ability to adapt to nursing home living, and vice versa.

The findings of all three studies in this doctoral research are now discussed together in chapter 6 (overall discussion) along with presentation of my recommendations and overall conclusion.

## Chapter 6: Thesis Overall Discussion

In the present chapter I first revisit the aims of this doctoral research. Then, in light of the contextual review, I critically discuss the findings of each of the three studies conducted and the impact of these findings when considered as a single integrated body of work. This chapter is organised into four sections: first, 'research aims'; second 'wider societal discourses and their influence on the nursing home environment' (study 1); third 'embodiment of wider societal and organisational discourses and their influence on nursing home staff (study 2) and nursing home residents (study 3); and fourth 'the implications of present findings in practice'.

By means of summary, each of the themes identified in data for each of the three studies is presented in table 12 below:

**Table 12: Summary of themes for each of the three studies conducted during this doctoral research**

Study	Theme Name		
	Theme 1	Theme 2	Theme 3
<b>Study 1</b>  Ethnographic Observations	Medical influences on the environment and staff working practices	Psychosocial interaction and the effect of limited resources	Legislation and language as power
<b>Study 2</b>  Focus Group with Nursing Home Staff	Obligate Carer	Resentful Carer	Constrained Carer
<b>Study 3</b>  Interviews with Nursing Home Residents	Constructions of Care	Journey into the Nursing Home	Adjusting to Nursing Home Living

## Section 1- Research Aims

The overall aim of the research was to consider how wider political/socio-economic and cultural discourses influenced the nursing home environment, and how such discourses aligned with the value systems of nursing home care staff and those of residents. This was a small study conducted in three nursing homes in the North of England, and as such may not be representative of all nursing homes. The present research has shown a lack of compatibility between the medically-driven, rationalised and highly regulated care delivered at the organisational level in participating nursing homes, and the relationship-focused ethic of care purported by staff and residents. My findings reveal that the nursing home is a contested space on multiple levels, not just in terms of its physicality and working practices (a hospital or home) but also embodied tensions associated with the role of care-giver (professional versus vocational self) and care recipient (independent versus dependent self) (see Diagram 4).

There were four aims of this doctoral research:

1. To explore wider contextual influences (at national 'macro-level') on nursing home care delivery at the nursing home organisational level including how such discourses impact on the environment and working policy and practice: informed by Study 1.
2. To explore what 'care' represents from the perspective of nursing home care-givers (staff) and care recipients (older residents): informed by Study 2, and Study 3 respectively.
3. Determine what barriers and enablers exist (and specifically what power relations are in operation) to the provision of nursing home staffs' and

residents' 'care' ideal in the nursing home context: informed by Study1, 2 & 3.

4. Informed by Study 1, 2 and 3, to develop recommendations that may inform or have the potential to improve the delivery of care for older people residing in nursing homes in England.

## Section 2 - Wider societal discourses and their influence on the nursing home environment

### Study 1: Observations in nursing homes for older people

The findings of the Observation Study presented in the first theme ('medical influences on environment, staff and working practices') showed that macro-level objectifying medical discourses and rationalised target-driven discourses that permeate NHS hospital care were also visible within participating nursing homes at both organisation (meso-level) and individual level (micro-level). At meso-level these medical and rationalised influences were manifest in the nursing home physical environment, organisational hierarchy, and working practices. For example, the medical extra-discursive evident in participating nursing homes (as a form of visibility) produced statements about older people as lacking capacity, as being cognitively and physically impaired, and increasingly dependent on others. In turn these statements further reinforced nursing homes as being necessary to provide care for older people in our Western culture. In accordance with Foucault (1972) statements and visibilities worked both independently and interactively to exert an effect or power in relation to the object of interest i.e., I found medical knowledge exerted power and dictated the nature of care delivered in participating nursing homes (see below section titled 'Medical knowledge as power').



### ***Ageism and objectification***

First, at the meso-level adoption of the macro-level medical 'objectifying' statements about old age were visible in the nursing home building layout, and equipment, fixtures and furnishings that were more representative of a hospital than a home. I also found staff constantly observed residents from central nurses' stations, and in one nursing home via CCTV. This replicated the institutional observation and monitoring of hospital patients and prisoners by those in positions of authority (Goffman, 1961), and was equivalent to the medical 'gaze' as theorised by Foucault (1963). The 'gaze' signifies a procedural and reflexive model of health and illness whereby people's actions are observed and judged by standards determined by the community they belong to. In the present scenario the community is the nursing home institution whose standards were found to be medically determined by influences at the macro-level, such as NHS policy and practices, and the people are nursing home staff, residents and visitors. I found that the medical 'gaze' empowered nursing home staff over recipients of care, and consistent with Kitwood's (1997) concept of 'malignant social psychology', represented 'objectification' and 'infantilisation' that I exemplify later in this discussion.

### ***Medical knowledge as power***

Within the present study, staff roles within the institution were found to be determined within a hierarchy based on medical knowledge/education that was visually reinforced by colour coded staff uniforms that complied with those of the NHS. Indeed, data from the staff focus group supports that care staff, and in particular nurses with a medical background, identified strongly with this 'professional' carer identity whereby nursing home staff felt duty-bound or

obligated to 'protect' residents. Although the attitude and behaviour of nursing home staff were well intended, such positioning of themselves as advocates confirmed their embodiment of medical and risk-averse legislative discourses, and their perceptions of older residents as being without voice, and thus without power. Inadvertently, and consistent with previous findings (e.g., Davies, 2007; Gilbert, Garratt, Kosowicz, Ostaszkiewicz, & Dow, 2021), present nursing home staff reinforced wider oppressive discourses at the point of care delivery, which is contrary to principles of person-centredness required to uphold personhood (e.g., McCormack, 2003,2004,2006,2011; and Nolan, 2004). Gilbert et. al's systematic review also found residents wanted to feel their complaints were heard by staff, and for them to be friendly and approachable rather than distant and professional (Adra et al., 2015; Bangerter et al., 2016; Boelsma et al., 2014; Bollig et al., 2016; Donnelly & MacEntee, 2016; Dybvik et al., 2014; Johs-Artisensi et al., 2020; and Rodr'iguez-Mart'in et al., 2013). However, they also found some residents preferred staff to be professional and competent and felt it appropriate for them to be more aloof (e.g., Bangerter, 2016), and valued staff having medical knowledge and clinical competence (e.g., Rodr'iguez-Mart'in, 2013; and Wang et al., 2016). This highlights the necessity to consider diverse variations in perspectives and circumstances, as present findings reflect only one sample of individuals within a specific context and snapshot in time. Also, the present predominantly White British cohort may not be representative of the views of residents in different cultures, both nationally and internationally.

That said, present findings demonstrate that this form of disempowerment of older people in long-term care persists, and thus requires intervention: I suggest potential recommendations for policy and practice at the end of this discussion. By applying Foucault's genealogy in the observation study, I found

that medical knowledge represents power in an institutional setting, and served to empower nursing home staff over older residents. This was achieved through self-regulation by staff and residents to the medically determined organisational hierarchy. This finding also supports Tronto's (1993; 1998) influential 'ethic of care' that suggests the fact that the older person is dependent on the carer automatically places the carer in a position of power. In the observations (study 1), staff focus group (study 2), and resident's interviews (study 3) this was found to compromise the autonomy of participating older nursing home residents within the carer/resident relationship. This could be seen where residents' choices were limited by medical discourses. For instance, where residents sat during mealtimes was pre-determined by staff based on the physical and/or mental capacity of residents, which supports my previous findings in nursing homes during mealtimes (Dunn, 2014). The impact of such medically-imbued discourse on participating nursing home staffs' and residents' experience of care (presented in the third section of this discussion: embodiment of wider societal and organisational discourses), served not only to reinforce staffs' position of power over residents, but also the organisations' power over both.

### ***Rationalised Care***

I have discussed how macro-level prevailing discourses of old age as a time of disability were visible in the nursing home institution's medically-driven policies and working practices that empowered staff over residents. In addition, the observation study findings (theme 1, sub-theme 3) showed routine working practices that were primarily task-focused. Task oriented care is primarily an 'efficient' and rationalised approach to care delivery that prioritises physical care needs over care recipients' psycho-social needs in order to maximise profits.

Running care delivery on a 'for-profit' basis has been found to impede quality care for nursing home residents including insufficient resources, services and equipment, and staff shortages (e.g., Carpenter, 2008; McCloskey, 2007; Royal College of Nursing [RCN], 2010; and Sheffield LINK, 2011). In support, my observation study findings showed that older immobile residents were left unattended while nurses and Care Assistants engaged in physical routine tasks such as re-stocking of linen cupboards, and the routine completion of paperwork related to resident's physical care (e.g., resident care plans and charts). Similar to NHS nurses (Cunningham, 2012) paperwork took up to one sixth of participating Care Assistant's working hours, which restricted the time nursing home staff had to interact socially with residents and meet their psychosocial needs. Gilbert et. al. (2021) also suggests residents were dissatisfied with routine working practices, which failed to take into account their individual needs and preferences (Donnelly et. al., 2016; Hasegawa & Ota, 2019; Wang, 2016), and represented reduced independence and quality of life for residents (Heid et al., 2016; Moyle et al., 2015; Palacios-Ceña et al., 2013; Popham & Orrell, 2012). However, some residents felt the loss of independence in the care home was preferable to the risks of and vulnerability they experienced living alone (Palacios-Ceña, 2013) a feeling that was expressed by a minority of residents in the present doctoral research.

Additionally, the focus group data suggests staff felt torn between their 'professional' obligation to deliver care in accordance with the requirements of their employer, and their own 'vocational' ethic and desire to care deeply for residents. In order to redress the imbalance while delicately taking into account their own needs, nursing home staff gave more to residents at the psychosocial level during their own time. However, this was only where the disposition of

residents and staff was compatible, and usually excluded residents that were already socially isolated and marginalised within the nursing home community. This is mirrored by other studies that found some residents prefer close relationships with staff (e.g., Artisensi et al., 2020), whereas others prefer staff to be more aloof and professional (e.g., Bangerter, 2016). I also found rationalised/routine working limited participating residents' choices about when to eat, bathe, sleep, and socialise: the impact of this on residents is presented in more detail in section 3 of this discussion.

The rationalised care ethic I found in participating nursing homes was monitored and enforced externally by the Care Quality Commission and Local Authority regulators, and internally by nursing home management. For example, observation and focus group data showed that nursing home staff prioritised the completion of documentation related to care-giving and dispensing medications over social activities. These rationalised discourses prohibited participating nursing home staff from using their initiative, sharing knowledge with each other, and interacting with colleagues and residents other than to meet residents' physical care needs. In previous research in nursing homes practices found to impact negatively on the physical wellbeing and autonomy of frail older residents included overnight care (Flick et. al. 2010; Kerr et. al. 2008), staffs' inadvertent restriction of residents' choices (Davies, 2007), and physical demands on staff and staff shortages (Dunn, 2014).

In practice these rationalising discourses equate to person-centred care that focuses on the individual and fails to consider the relational, social and contextual aspects of care that many suggest are central to successful 'individualised' care outcomes (Brown, 2008; McCormack, 2004, 2006, 2011; Nolan, 2001, 2004; and Ryan, 2008). Rationalised care ignores the theoretical underpinnings of dignity

conserving 'relationship-centred' care that is purported for long-term care of older people (see definitions of dignity and models of care in Chapter 1) that is dependent upon the development and maintenance of positive relationships. Rationalised care is often associated with a 'for-profit' business model (Brown, 2008), and present findings support that private sector care provided in participating nursing homes was aligned with this model.

### ***Legislation and Language***

The third dominant extra-discursive I identified in participating nursing homes, and as outlined in the contextual review chapter, was that of risk-aversion born out of wider cultural positioning of older people as lacking capacity. Within Health and Social Care services in England, protection of those positioned as lacking capacity, such as older people, is overseen by regulatory bodies such as the Care Quality Commission (2009; 2011b). In nursing homes this was made visible through legislative interventions (e.g., Mental Capacity Act, 2005, 2007; Health and Safety at Work Act, 1974), that were introduced in England with the aim of empowering nursing home residents and safeguard them against institutional abuse. In participating nursing homes, I found such legislative, risk-averse discourses served to reinforce these wider discourses of ageism that were made visible in the nursing home physical environment, and policies and working practices. Similar to medical and rationalised discourses previously discussed, legislatively-driven 'risk-averse' discourses were evident in nursing home signage (Health and Safety related), physical restrictions (e.g., coded door locks), and staffs' ageist language and behaviour (e.g., infantilising and labelling residents based on their 'incapacity'): all served to restrict residents' choices and independence. For example, I found these macro-level medical and risk-averse

discourses restricted residents' personal choices about when and where to smoke, and what to eat. Thus, in addition to medical and rationalised discourses, the nursing home organisation and staffs' embodiment and interpretation of wider legislative discourses represented power over residents.

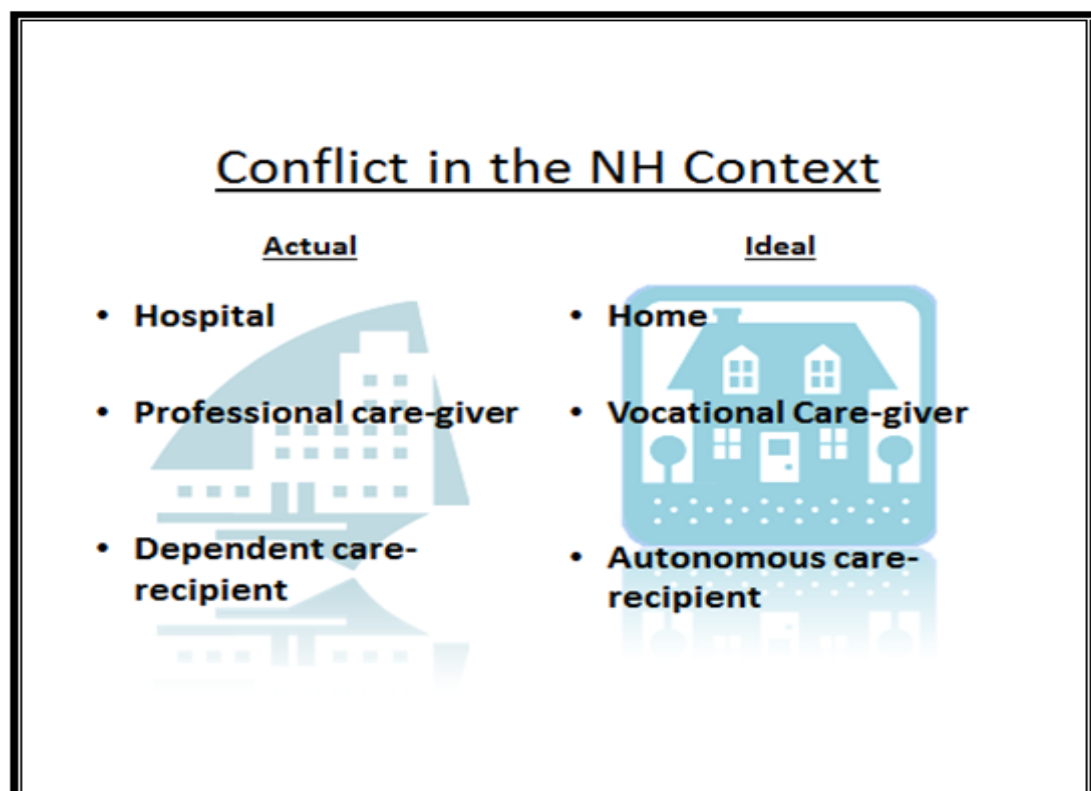
In contrast, Michele Crossley (2010:28) notes that such policy, regulatory and legislative discourses are synonymous with the United Kingdom's postmodern capitalist society and aim to promote individual agency, thereby opposing prohibitive modernist discourses of rationality. They represent a more procedural and reflexive model whereby individuals can contribute to knowledge and make decisions, and are judged by the standards of the community to which they belong. Therefore, rather than comply with existing order we construct order through a process of self-regulation to community norms (Hardey, 1998). However, as found in participating nursing homes, rather than promoting autonomy for individuals such discourses are also indicative of subjectification.

Subjectification is an extension of the organisational 'gaze' in the form of reflexivity and self-regulation to wider discourse of control and discipline, which serves to restrict rather than promote agency (Bury, 1991;1998; and Foucault, 1977). This is supported by other studies where residents with dementia felt they were prevented from going outside or making decisions due to the enforcement of risk averse policies by some staff (Cho et al., 2017; Harrison & Frampton, 2017; Moyle et al., 2011, 2015; Potter et al., 2018; Walker & Paliadelis, 2016). Others found conflict exists between staff and residents due to the disparity between staffs' desire to reduce risk, and residents' desire to engage in activities they find fulfilling (Kang et al., 2020; and van Hoof et al., 2016). The criticism by the Care Quality Commission that routine working dominates NHS hospital and nursing home care (CQC, 2011a) is ironic in the context of present findings, which

suggest the adoption of a task-focused approach is primarily the embodiment of wider medical, fiscal, and 'regulatory' discourses that are enforced by organisations such as the Care Quality Commission. That said, the 'for profit' nature of private sector care home provision drives the need for efficiency and thus further reinforces routine working that in turn limits the choices available to service users.

To summarise, the medically-driven, rationalised, for-profit and risk-averse model of care that was found in participating nursing homes collectively represent an impoverished environment that is not conducive to relationship-centred care (Kitwood, 1997; Mc. Cormack, 2011; and Mitchel, 2015). I found participating nursing homes to be a contested hybrid space that professed to be a 'home' for residents yet resembled a hospital or prison, and all the while was a place of work for staff (depicted in Diagram 4).

**Diagram 4: Conflict at organisational and individual levels in the nursing home context.**





Within the nursing home community there was pressure to conform to institutional rules that reflected wider cultural discourses of ageism and discrimination that resulted in tension for both staff and residents. I now discuss how such tensions were manifest and negotiated in an environment that placed the nursing home organisation in a position of power over staff, and both in a position of power over residents.

Please note that these findings were both supported and contradicted by other studies internationally (Gilbert et. al., 2021), which suggests that individual resident's perspectives and contexts must always be considered when planning and delivering care, and when conducting research in this cohort. Consideration should also be taken for the fact that the observation study was conducted and data interpreted by only one person, the author. The observations in each nursing home were also carried out over a relatively short period of 3-4 weeks during Spring, and as such may not be representative of the care practices that may vary over time. It is therefore recommended that future observational research in this cohort /context be conducted and interpreted by more than one individual to avoid the potential for researcher bias. Also, observations would ideally be conducted over a longer period of time and would include observations overnight to reflect daily and seasonal variations in care delivery should they exist.

### Section 3 - Embodiment of wider societal and organisational discourses and their influence on nursing home care-givers (staff) and care-recipients (older residents)

My analysis of nursing home observation study data drew on Foucauldian Discourse Analysis and found that wider medical, rationalised and legislative discourses were embodied at organisational level. At the next level of Thematic

Analysis, and due to a paucity of literature, I explored how such discourses influenced care at the point of delivery in order to understand if, how and when power is exerted and whether it is to the detriment of nursing home residents.

## Study 2: Staff Focus Group

### ***Self-regulation of staff to nursing home discourses***

The aim of the focus group study was to determine what ‘care’ and the role of care-giver meant to nursing home staff. Participants’ accounts highlighted that their care ideology was inextricably linked with their identity as a care-giver. For nursing home staff, care involved more than attending to the physical needs of residents, care meant engaging with residents at a deeper, more emotional level. Consistent with Tronto’s ethic of care this required emotional investment, giving through loving and nurturing residents over time, and developing a relationship based on trust: a relationship that extended to others involved in care e.g., other staff and residents’ visitors. Therefore, participants’ perceptions of care and care-giving corresponded with previously outlined definitions of dignity and care, and existing relationship-centred theories and models of care (see Chapter 1) that consider care to be contextually influenced.

In relation to the role of care-giver, focus group participants, and in particular nurses, portrayed care-giving as value laden and constructed their care-giver identity as both ‘Vocational’ and ‘Professional’ in nature; I refer to this dual identity as the ‘vocessional’ care giver. However, participants’ talk about care and care-giving was inconsistent, which also reflects Tronto’s (1998) Ethic of Care and previous research in nursing homes for older people (e.g., Dunn, 2014) that suggest conflict is central to the role of care-giver. In the present study

participants experienced conflict on three distinct yet interconnected levels that were presented in three themes: Obligate Carer; Resentful Carer; and Constrained Carer.

The first theme 'Obligate Carer' reflected how participants experienced difficulty balancing their dual carer identity through a sense of obligation to maintain their care values as a 'vocational' caring person, juxtaposed their moral and contractual obligation as a 'professional' care-giver to meet the needs of residents and others involved in care. The fact that present and other research in care homes has found some older residents prefer staff to be more aloof and professional (Bangerter, 2016), whereas others prefer them to be friendly and approachable (Adra, 2015; Bangerter, 2016; Boelsma, 2014; Bollig, 2016; Donnelly, 2016; Dybvik, 2014; Johs-Artisensi, 2020; & Rodri'iguez-Mart'in, 2013) further cements this 'vocational' dilemma for nursing home staff. Staff participants' inner struggle to balance their 'vocessional' care-giver identity was heightened when they experienced emotional feelings stemming from their relationship with care recipients: for example, feeling distressed and upset about the death of a resident. Consistent with previous (Cohen-Mansfield, 1995; and Fulton, 1996) and more recent findings in nursing homes (e.g., Adland, Gripsrud, Lavik Ramvie, 2021), participating staff suppressed these feelings and distanced themselves to maintain their status as a Health Professional and balance their own needs with those of others. Throughout participants' discourse such conflict negatively influenced their self-reported 'Emotional feelings' (e.g., low morale and mood), 'Extra-emotional feelings' (e.g., heightened fatigue and anxiety), and aroused their 'Feelings of knowing' (e.g., mistrust of co-workers), which exemplified the theory that feelings are both embodied as well as externally

influenced (e.g., Cromby, 2007;2011). Participants' accounts suggest that for nursing home care-givers 'feelings' are integral to care and care-giving.

Although feelings have been acknowledged within previous relationship-centred theories and models of care (e.g., McCormack, 2006; Nolan, 2001), there is little attention paid to how such emotional conflict can be resolved in practice. Doing so is particularly important as recent findings support that when care staff suppress their feelings to appear professional, they are more likely to experience fatigue, burnout, and moral distress leading to higher absenteeism and ultimately higher staff turnover (e.g., Adland, Gipsrud, Lavik, & Ramvie, 2021). In contrast, present focus group participants' shared care values seemed to provide cohesion and a sense of camaraderie that provided a buffer against the stressors associated with the value laden nature of care work. Despite this, present findings suggest that nursing home staffs' attempts to deliver relationship-centred care in practice resulted in the same negative emotional outcomes for them that have since been reported elsewhere (Adland et. al., 2021), and adversely affected participating staffs' relationships with nursing home residents.

The second theme 'Resentful Carer' demonstrated how participants struggled to maintain their 'vocessional' carer identity against a backdrop of historically, culturally and socially constructed negative discourses about, and undervaluing of old age, older people and care work. These extra discursive influences were embodied where participants' felt undervalued, unheard, and overworked. This mirrors findings of inadequate pay and working conditions for staff engaged in home care provision for older people in the United Kingdom (Equality and Equal Rights Commission, 2011). Present participants' perceptions of these constraints were consistent with burnout previously found among care workers (Maben et al., 2007). Burnout in care staff increases staff absenteeism

and staff turnover (Banaszak-Holl, 1996; Adland, 2021), and prevails still in participating nursing homes evidenced through my observation of staff shortages, and participants' (staff and residents) reference to the regular use of agency staff due to low staffing levels. Other studies also support that staff shortages and unfamiliar agency staff are perceived by care home residents as having a negative impact on the quality of care they receive: indeed, residents in other studies also sympathised with staff (Bollig, 2016; Dybvik, 2014; Nakrem et al, 2013) and withheld requests for support to reduce the burden on staff (Nakrem et al., 2011).

In contrast, flexible working, carer involvement in decision making and care planning, and improving communication between nurses and Care Assistants serve to reduce staff turnover Banaszak-Holl (1996) as well as improving dignity conserving care (e.g., Gallagher, 2017). Action research has also been found to empower care givers, promote partnership and a sense of being valued, and increases staff enthusiasm (Gallagher, 2017). In the present thesis, breaches of confidentiality by at least one manager, and an ineffective safeguarding system were found to perpetuate a culture of mistrust, mirroring similar findings in the NHS (National Guardian's Office, 2018). Present findings also highlight the failure of current safeguarding systems to prevent care workers who breach good care practice from returning to work in the private care sector. Such an environment is inconsistent with the relationship-centred ethic of care that is currently supported in long-term care for older people (Brown, 2008; McCormack, 2011; and Nolan, 2006) and potentially compromises the safeguarding of nursing home residents. This illuminates the failure to ensure confidentiality, and introduces the argument to maintain the anonymity of whistleblowers in nursing homes in order to promote

the early disclosure of malpractice: such anonymity is currently an option within the NHS (National Guardian's Office, 2018)

The third theme 'Constrained Carer' highlighted how staff participants' ability to balance their own needs with those of others involved in care was compromised by external material and structural constraints that included limited resources and excessive workload. Where care-givers struggled to retain their 'Obligate carer' self-identity they adopted rhetorical blaming as a strategy to justify their 'resentful' and 'constrained' carer identities, which they generally positioned as external to them. Discord was evident in participants' accounts where they perceived different care-giver job roles and the distribution of resources to be unequal. Such inter-group conflict has the potential to disrupt the sense of camaraderie and team working those participants shared and considered to be central to the delivery of care in practice. In institutional care for older people action research has been shown to improve moral and team working (Gallagher, 2017). Additionally, an appropriate care environment is deemed necessary for relationship focused care to exist (e.g., McCormack, 2006).

Although present findings of inequality suggest that conflict may be attended to by fairer re-distribution of resources, staff participants also encountered embodied barriers to the delivery of relationship-centred care, including staffs' dispositional preferences for some residents. Staff negotiated this by giving equally to residents in their 'Professional' care-giver role, and giving more to residents they cared for deeply in their own time and in their 'Vocational' care-giver role. Although this seemed to balance the dual needs of care-givers, arguably it is representative of unequal care for residents that extended beyond

care at the material or structural level. This inequality is especially pertinent considering that participating residents, and residents in studies internationally (e.g., Gilbert et. al., 2021) attribute staff attitudes and their behaviours toward them as an indicator of quality of care. As previously mentioned, this is difficult for nursing home staff to negotiate as some residents prefer staff to remain aloof and professional (e.g., Bangerter, 2016), whereas others want staff to be friendly and approachable (e.g., Johs-Artisensi, 2020).

Despite this, models suggest that dignity conserving care skills can be taught to care givers and delivered successfully irrespective of dispositional incompatibility with those in receipt of care (e.g., Chochinov, 2007). However, in this doctoral research staffs' accounts of the training they received indicate that there was a lack of context-specific training. Some suggest this issue may be addressed by the provision of bespoke training for nursing home staff by care commissioners and care providers (e.g., Sheffield LINK, 2011). Despite numerous recommendations, present findings suggest that the humanistic nature of care and care-giving, and the complicated, messy, and often unpredictable nature of human relationships (alluded to by Tronto over thirty years ago) remains prevalent in participating UK nursing homes.

It is clear that nursing home care-givers embodied and endeavoured to adhere to a relationship-centred ethic of care. However, my focus group study findings support that the 'for profit', rationalised and medically-driven model of care was deeply engrained in the private sector nursing home culture, and that staff were obliged to self-regulate to it in their capacity as a 'professional' carer. Where nursing home care-givers strove to integrate two such disparate and incompatible care philosophies they experienced an inner moral and ethical conflict that was irreconcilable, and had a negative influence on their emotional

wellbeing. This tension was manifest through nursing home staffs' feelings of guilt, frustration and self-criticism for not giving enough relationally, and ultimately resulted in them experiencing fatigue that may lead to burnout.

It is perhaps worth noting some methodological considerations here. First, the focus group comprised of staff from only one of the three participating care homes and thus are not necessarily representative of the beliefs about care in nursing home staff more broadly. It is also important to note that there were two dominant voices in the focus group and to some extent it may have meant that the discussions of care were guided by these voices. However, the findings reported here are consistent with findings reported elsewhere in the literature (e.g., Adland et. al., 2021), and thus warrant serious consideration.

### Study 3: Interviews with residents

#### ***Self-regulation of residents to nursing home discourses***

So far, my findings demonstrate that the environment, policies and working practices in participating nursing homes represent an impoverished environment that is not conducive to 'dignity-conserving care' for older people. In contrast, nursing home staffs' personal 'vocational' care ethic was aligned with 'relationship-centred' care that academics, policy makers and older residents themselves deem appropriate for long-term nursing home care. In practice, staffs' obligation as a 'Professional' care-giver meant participating staff self-regulated to inherent, impoverished nursing home care discourses. This conflicted with their 'vocational' care ethic, which, set within a rationalised belief system that undervalues care work, resulted in nursing home staff becoming resentful and fatigued.



### *Constructions of care*

In interviews with residents, I found participants self-regulated to conflicting discourses of care consistent with Tronto's ethic of care, and that their care ideology was aligned with the relationship-centred care models outlined in Chapter 1. First, residents portrayed care as existing in the context of a relationship with at least one other person based on a foundation of empathy, kindness, and trust, which is consistent with other studies included in a recent literature review (Gilbert et. al., 2021). For present residents this included long-term relationships with relatives and friends, and more recent relationships with other residents and nursing home staff. Present findings suggest that for residents the deepest caring relationships exist most often with people beyond the physical boundaries of the nursing home: with their family and close long-term friends. This supports my observations study findings that the environment in participating nursing homes is not conducive to building new positive relationships: at least in the short-term when residents were found to feel most isolated. This is of concern as interpersonal bonds protect older people from depression (Hinrichsen, 2008;2010), Difficulty building positive relationships may also account for the high incidence of depression in residential care in the UK, which is between 15-25% (McCabe, 2009). Recent publications suggest lack of control over their own privacy (such as overcrowded and noisy communal spaces, and being unable to lock their own bedroom) leaves residents feeling vulnerable to abuse and violence from other residents (Gilbert et al., 2021). Present findings suggest that where residents developed new friendships with other residents, most expressed this as being at a superficial level, partly due to dispositional incompatibility, and partly to avoid the pain associated with loss that residents know they will inevitably experience as death looms closer. This

sense of loss is consistent with previous findings among older cohorts (e.g., Bayer, 2005; Franklin et al 2007) including nursing home residents (Hall et al, 2009).

In the present study, all fourteen residents had experienced loss prior to and since entering the nursing home including their home, family, friends, pets, and their own autonomy and capacity. I found that death and/or anticipation of death represented conflict for both nursing home staff and residents, and the emotional pain associated with loss due to bereavement was a barrier to building positive relationships. Nursing home staff avoided, ignored, or did not express their emotions in order to uphold their obligation to be 'Professional', which was counter to their 'Vocational' desire to care deeply. Avoiding and ignoring residents is contrary to models (e.g., Chochinov, 2007) and research (e.g., Hall, 2009) that suggest kindness, respect and dialogue are integral to dignity conserving care. For participating residents who lacked or struggled to maintain caring relationships, and/or to develop new relationships within the nursing home, being devoid of the positive experience that caring relationships bring was portrayed as having a negative impact on their mental well-being. This was manifest through residents' inability to develop a new sense of selfhood, or feel settled and content within the nursing home community. As building and maintaining positive relationships rather than prioritising physical care is considered integral to long-term care for older people (e.g., Nolan, 2006; McCormack, 2011), embedding adequate support for staff and residents to build and retain relationships and cope with loss is imperative. Despite relationship focused models of care and policies purporting the importance of co-production (e.g., NHS England & NHS Improvement: The Framework for Enhanced Health in Care Homes, 2020),

relationship-focused care remained elusive in participating nursing homes and others internationally (see Gilbert et al, 2021).

At organisational level the barriers residents experienced were often due to conflict born of residents' reluctance or inability to self-regulate to the institutional rules of the nursing home community. I found that over time residents who embodied institutional and staffs' discourses of old age as incapacity began to adopt a passive compliant role: this appeared to smooth their transition into nursing home living. I found that residents with impaired cognitive capacity, less resistance to nursing home community discourses, and a more gregarious temperament were more likely to adopt a passive compliant role. In accordance with Goffman's (1961) 'total institution' being compliant involved residents adhering to the nursing home community rules by relinquishing control. These included residents adhering to medically determined schedules, such as nurses dispensing residents' medications during mealtimes. The practice of dispensing medications and seating residents where most convenient for staff during mealtimes has previously been found to interrupt one of the few opportunities that residents had for social interaction within the nursing home (Dunn, 2014). During interviews, residents themselves spoke of being prohibited by the nursing home community (staff and other residents) from engaging in activities that positively reinforced their self-identity and gave them pleasure, such as smoking. The present research found self-regulation of the nursing home community to wider prohibitive risk-averse, medically driven, and legislatively reinforced discourses resulted in a reduction in residents' choice and independence, and was thus disempowering. This finding is supported in other studies conducted since 2010, where being unable to make decisions left residents feeling dissatisfied (Gilbert et al., 2021). To comply with existing models of care, and especially Mc

Cormack's 'care environment' participating nursing homes would need to re-think the physical environment and working practices. This includes minimising overt visibilities of medical, rationalised, and risk-averse discourses: for example, removing nurse's medicine trolleys from the dining area during mealtimes and exploring alternative ways to dispense residents' medications.

These disempowering discourses, and residents' compulsion to adhere to them are of concern as previous research found negative outcomes for nursing home residents with limited autonomy, including increased suicide rates (Osgood, 1992) and reduced physical wellbeing (Davies et al., 2007). Additionally, the physical layout of nursing homes and the discernible presence of medical equipment in the observation study emphasised nursing home residents' incapacity rather than their capacity. This suggests that both organisational and individual level the nursing home community self-regulated to higher level discourses of disability and incapacity, such as those portrayed nationally in the media and in Health and Social Care policies (e.g., Hatch, 2005; Kane et al., 2004). In one study, a resident suggested staff are more likely to neglect residents that lack capacity and self-advocacy, such as those with dementia or other disabilities (e.g., Kang et al., 2020). Present observation and focus group study data indicated that staff felt disempowered to support residents' emotional needs. This was due to pressures from nursing home management to prioritise residents' physical care needs, and insufficient investment in staff training to support the context-specific needs of both staff and residents e.g., coping with loss due to bereavement. This emphasises the need to ensure staff receive appropriate training bespoke to this context and cohort.

For all residents, I found receiving care was guilt-laden, and indicated their self-regulation to wider cultural discourses old age as a burden that was made visible through rationalisation and scarce resources in participating nursing homes. Such self-regulation left residents feeling obliged to justify that they were worthy to receive this scarce 'care' resource. Residents justified themselves by continuously anchoring their current 'dependent-self' to past good deeds, and to those of people closely associated with them such as family members. Participating residents felt compelled to contribute by 'giving' where they were able within the limits of their own personal capacity, and the constraints placed upon them within the nursing home. For example, residents lacking physical capacity demonstrated they were worthy of 'care', that they 'cared about' others, and expressed their gratitude for 'receiving-care' at the psychosocial rather than the physical level. This included giving gifts such as sweets, and demonstrating kindness, humour, thoughtfulness, and listening. For participating residents, continuing to give in ways they could not only showed they cared, but also re-enforced their self-esteem and helped cement existing and build new mutual care relationships. This is supported by further studies where engagement in activities, decision making and risk taking were identified as bolstering residents' self-efficacy and self-esteem (e.g., Abbott, 2018; Johs-Artisensi, 2020; Kang, 2020; van Hoof et al., 2016; and Palcios-Cen'a et. al., 2016).

Residents' perception of care as a mutual, two-way relationship is consistent with existing care models (Kitwood, 1997; McCormack, 2006; and Nolan, 2006), as were the accounts of participating nursing home staff. Although 'giving' in return for care received was a positive affirmation of self-esteem for residents, the motivation to give was partly motivated by cultural discourses of old age as a burden, which bore feelings of guilt for residents and impacted

negatively on their self-worth. Present findings therefore confirm suggestions (e.g., Tronto; 1997; Crossley 2010; Gallagher, 2017) of the need at wider societal level to reposition old age as a time of capacity and value rather than incapacity and burden.

Additionally, where residents expressed that a mutual care relationship existed with nursing home staff or other residents this personal bond had grown over time and was based on trust. This supports suggestions that trust is required for positive Health Professional/patient relationships to thrive (e.g., Brown, 2008). Present findings suggest that some residents experienced low mood due to difficulties re-defining their identity as a member of the nursing home community, especially in the first few months after entering the nursing home. Similar negative experiences have also been expressed by nursing home residents beyond the UK, with some residents suggesting that staff fail to trust that they are able to make decisions for themselves, resulting in conflict: especially when residents choose to participate in activities staff perceive as 'risky' (e.g., Kang, 2020; and van Hoof 2016).

In the present study, residents who were still unfamiliar with and had not yet embodied the nursing home community rules, and/or were reluctant to do so, had experienced staff being physically and/or verbally abusive towards them during personal care, and had been ignored by them and accused of lying. Similarly, residents felt alienated by other residents and family members disbelieving them. Consistent with accounts from staff focus groups, negative interactions existed where the disposition of other residents and nursing home staff were incompatible with that of the 'new' resident. When a resident's family member disbelieved them, the resident was positioned as over-reacting, which failed to acknowledge

the resident's feelings and further reinforced the power the nursing home community held over them. This is equivalent to Kitwood's concept of 'malignant social psychology', and contrary to all models of care previously discussed that are deemed suitable for institutional care of older people. When residents' family believed and supported the resident's account and made a formal complaint to the nursing home manager, this redressed the imbalance: although only temporarily. Residents' narrative confirmed that over time this power imbalance was sustained through and was exacerbated by rationalised care: such as abusive dismissed care workers returning to the nursing home as agency staff during times of staff shortages. This is consistent with previous literature that suggests rationalised 'instrumental' care such as that provided in hospitals fails to nurture trust in the relationship between care providers (Health Professionals) and care recipients (Brown,2008). This supports the need to promote trust early in the resident's nursing home journey to facilitate relationship-centred care delivery, and acknowledges the part family and visitors can play in supporting their loved one.

At the individual level, when residents were unable to develop a relationship with staff, I found it was often due to dispositional incompatibility and/or staff failing to show empathy, kindness, or understanding of residents' individual care needs. This sentiment was also reflected in staffs' accounts during the focus group study as previously discussed, and in the views of residents in other studies (e.g., Donnelly, 2016; Hasegawa, 2019; and Wang ,2016). Nursing home care providers are in a position to address this issue by paying attention to whether residents have developed such caring relationships with other residents or staff. In order to foster such relationships Chochinov (2007) suggests nursing home care providers should ensure they, and staff, attend closely and chronologically

to all four principals outlined in his Dignity Conserving Care model i.e., improving attitude, behaviour; compassion and dialogue with residents. Even where the disposition of staff is incompatible with that of residents, Chochinov considers it possible, through appropriate training, to improve staff attitudes and behaviour and develop compassion and dialogue to promote dignity conserving care relationships.

Consistent with existing models of care (Chochinov, 2007; McCormack, 2006, and Nolan, 2006) I found that residents perceived staff to care about them when they mirrored their own values of respect, understanding, patience, and humour. Residents also considered the care they received to be of better quality if the formal 'care-giver' was knowledgeable and experienced in their role. This supports previous findings that in nursing homes, nurses with experience received the highest scores in caring (Persky, 2008). More recent research also found that experienced staff were perceived as more caring by residents (e.g., Bangerter et al., 2016; Dybvik et al., 2014; Palacios-Ceña et al., 2013; Rodr'iguez-Mart'ın et al., 2013; van Hoof et al., 2016). For present nursing home residents, where the formal 'care-giver' did not meet these pre-requisites, residents were more likely to complain about the standard of care they received. Complaints ranged from a lack of attention to detail through to stories of being bullied or handled roughly by staff, which again was most evident when residents were new to the nursing home.

To summarise, for residents the transition into nursing home living was a difficult path to negotiate. To become fully integrated members of the nursing home community, present findings suggest that residents must desist from resisting and instead resign themselves to, or fully accept, their role of care recipient. Consistent with existing literature (Goffman, 1961; and Crossley 2010)



this transition also required residents' compliance with the social and formal rules of the 'total institution'. Residents that resisted or failed to comply were found to experience tensions in their relationship with family, nursing home staff, and other nursing home residents. These tensions equated at least to confusion for residents, and at worst to bullying: both scenarios represent a failure by the nursing home to deliver dignity conserving care. Additionally, I found that the length of time residents had lived in the nursing home may influence residents' sense of belonging to the nursing home community, with residents living in the nursing home for 12 weeks or less more likely to feel disenfranchised, those 13-26 weeks more likely to feel able to participate, and those over 26 weeks more likely to feel fully integrated: irrespective of nursing home, or the amount of control the resident had over the decision to enter the nursing home.

Additionally, residents may be more vulnerable to feeling disenfranchised in the first three months of nursing home living when they experienced uncertainty about the social and formal rules of the community; had insufficient time and/or resources to re-build their sense of self-identity in their new role as care-recipient in the nursing home context; and, had to negotiate all this in conjunction with recent major loss (es). Loss for residents included the loss of their self-identity and independence; physical and/or cognitive capacity; a significant other due to death or illness; and their home, possessions, and wider/familial social networks. Given the prevalence of such loss prior to entering the nursing home, the transition to nursing home life would be extremely challenging even if the environment was aligned with residents' care ideology: the fact that it is not served only to further erode residents' already frayed sense of personhood.

## Critique of the Present Research

This PhD has been undertaken over a period of 10 years. Initial literature was collected in 2010/2011 at the beginning of this journey when data was collected for the three qualitative studies. Final thesis revisions were submitted in 2021. The thesis offers both a snapshot in time and an opportunity to also reflect on how research and societal views have informed our conceptions of this space over a decade. The initial literature review represents the state of knowledge at that time. In revisiting the literature, a decade later, it was significant perhaps that, given the importance of this sector in providing for the needs of some of the most vulnerable individuals in society that there was not the volume of research that I would have expected. I was aware that many of the original references felt outdated but struggled to find papers that were more current. A systematic review in 2021 of qualitative studies exploring residents' perceptions of the quality of care outside the UK was published at the time this present thesis was submitted. Interestingly, the findings of this review (Gilbert et. al., 2021) produced nine themes that closely mirror those of the present thesis. Gilbert et. al.'s (2021) review found that at organisation level adverse influences on 'quality of care' included poor staffing levels, a clinical environment, insufficient activities for residents; routine systems of care delivery; risk averse policies and practices, and failure to cater for residents' culture and spirituality. At the personal level insufficient resident choice and involvement in decisions, poor staff attitude, and a lack of continuity of care by the same staff also adversely influenced residents' perceptions of care quality. This suggests older residents living in care homes globally share the same ideology of 'care' and 'home' that are synergised within a personalised and relationship-centred approach: this applies as much now as

it did 10 years ago. As such these building blocks should be considered the foundations on which all care homes should be built.

From a methodological perspective my use of ethnographic observations, focus groups and one-to-one interviews, visual methods and object elicitation within the nursing home context, facilitated the collection of rich qualitative data that portrayed the life-stories of participants. Adopting a Critical Realist approach and Thematic Analysis successfully illuminated the story of the nursing home community, and enabled me to identify wider contextual influences that gave 'birth to the nursing home' and influenced its physical space, and policy and practices. The methodology gave insight into the nursing home as a living community, and also the lived experiences of its inhabitants. I would therefore recommend this approach in future research to further inform our understanding of this context and cohort. Additionally, as action research has successfully promoted dignity conserving care in the care home context (Gallagher, 2017), integrating present methods within an action research approach may also facilitate further exploration of present findings from a strategic perspective.

It should be noted that the general limitations of focus group and one-to one interview methods apply to the present doctoral research. For example, the analysis is qualitative and interpretive, and therefore cannot infer any causal effect. Also, as noted above the focus group comprised of only a small sample of four nursing home staff in one out of the three participating nursing homes and thus may not be representative of the views of staff in other participating nursing homes. Also, there is the potential for researcher bias: particularly as participants' perspectives were analysed by a single researcher (I the author) with over 10 years' experience working as a nurse in nursing homes. Additionally, the

voice of two of the four focus group participants was particularly forthcoming (i.e., the nurse working day shifts and the Activities Coordinator) compared to the other two participants i.e., the nurse working night shifts and the Care Assistant. Similar limitations can be applied to the resident's interviews study (Chapter 5). Although thorough and rigorous data collection and analysis methods were adopted, and all participants' perspectives were reflected to negate these factors, I recommend that subsequent research should obtain the view of a greater number of staff and residents in more than three nursing homes across a wider geographical area. Additionally, there should be more than one researcher involved in data collection and analysis. Despite the limitations of these studies, many of the findings were congruent with other studies conducted across more than a decade within the UK and internationally, suggesting that the views of present participants are consistent with others in the same cohort, context, and across time.

Present findings suggest that (in the context of the 'relationship-centred' care model) mapping residents' characteristics of acceptance of nursing home living alongside the duration residents have lived in the nursing home, may provide an indicator of the resident's sense of belonging within the nursing home community. This data may inform future research to promote a smoother transition for residents entering into nursing home care. Caution must be taken though not to over-generalise and pigeon-hole residents as it is clear from qualitative interviews that, although much overlapped, each resident's experience was uniquely different. This supports other findings of the importance of ensuring each resident's specific needs are met through involving them and their significant others when planning and delivering care. Also, due to the influence of the wider context on care home provision, a critique of the present thesis is the

omission of the perspectives of Health and Social Care commissioners and regulators, nursing home owners, nursing home managers, and the relatives/significant others of nursing home residents. Therefore it is recommended that future research should explore these perspectives in addition to those of nursing care home residents and staff.

My enquiry makes a contribution to knowledge by providing real life scenarios of good and poor care from the perspective of nursing home residents and the difficulties they experience when moving into a nursing home environment. Diagram 5 shows that the findings of this study are consistent with an ethic of care at wider level (Tronto, 1993; 1998), models of care delivery at organisational level (e.g., Nolan, 2006, and Mc Cormack 2011), and the need to provide staff with training in how to deliver the principles of such care in practice within the nursing home environment (e.g., Chochinov, 2007, and Hall, 2009). The challenge of existing models of care explored in this thesis present uni-dimensional perspectives which can, on occasion neglect the broader cultural, societal and policy frameworks all of which exert powerful influences on care. Without addressing these factors at macro, meso and micro level change cannot happen.

I suggest that by combining all three it is possible to deliver a bespoke template for care in nursing homes for older people that adheres to the relationship-centred care ideology of nursing home residents and nursing home staff in the present thesis. Combining this existing knowledge into one framework will help reduce the cumulative tensions experienced between nursing home staff and nursing home residents at the point of care delivery: and thus provide an environment in which dignity conserving care can thrive. Finding ways to

represent the complex interplay of these elements is important as it makes visible those hidden pressures, perceptions and attitudes that shape care. Of particular importance is a consideration of approaches to translating theory into practice through broader education and training opportunities. This is vital if positive cultures of care are to be created that offer the space for caring relationships to grow and enable individuals to flourish.



**Diagram 5: Proposed Nursing Home Care Framework by H. Dunn, 2021**

## Recommendations

Based on the findings of this research my recommendations are organised into three categories: recommendations to Government, recommendations to practice and recommendations to other academics undertaking research in this field

### Recommendations to Government

1. The study has highlighted the need for a shift in cultural values which reposition of old age as a time of capacity, and care work as valued and highly skilled profession.
2. Financial investment is required for the provision of: physical and psychological care services which were absent in the care homes explored in this study.
3. A review of electronic record keeping and the compatibility of these systems between Health and Social Care services is required to overcome the challenges relating to communication identified in this study. I suggest the introduction of the use of electronic recording of care at point of care delivery that automatically feeds through information relating to care (data) in real time to nursing home hierarchy, and then beyond to Health and Social Care information networks

### Recommendations to practice

1. Currently care homes are contested spaces and broader discourses regarding their role as a home are required. The outcome of these discussions needs to be reflected in the culture of care to ensure that

people living in care homes play a more active role in shaping the place where they live.

2. The design of these spaces and the organisational cultures need to better represent a community and a home rather than a clinical environment. This may necessitate reduction in routine working practices i.e., offering residents choices based on needs and not resources.

#### Recommendations to other academics undertaking research in this field

1. This study has highlighted the importance of researchers finding ways to hear the voices of older people living in care homes. Photographic methods have been shown to facilitate discussion and to give voice to individuals. There needs to be far greater openness and acceptance of the potential of such methods within the context of research with older people.
2. There is a dearth of research describing the complex ethical dimensions of undertaking care home research. There needs to be a more open discourse of ways that researchers who are new to this field can navigate the potential challenges that may arise in these so-called sensitive areas of research.
3. A wide-range of models in relation to 'good-care' in the care home context currently exist. However, as this study has highlighted there can frequently be a mismatch between academic theories and models and practice. Researchers need to consider the broader contexts impacting on care home environments and ways that research findings can be operationalised and translated into practice.



## Section 4 – Concluding Comments

This body of work has shown a lack of compatibility between the nursing home medically driven, rationalised and risk-averse culture and the relationship-centred personal care values of nursing home staff and residents. I found that the nursing home is a contested space, not just in terms of whether it is viewed as a hospital or home, but also staffs' conflicting 'professional' and 'vocational' carer identities, and residents' attempts to retain their independence within a culture which viewed residents through a medical lens of incapacity. I found prevailing discourses of incapacity gave rise to risk-averse legislative interventions that aimed to protect 'incapacitated' residents yet served to further disempower them. Nursing homes were found to self-regulate to wider cultural positioning of care as undervalued and 'women's work', and old age as a burden and was made visible through rationalised (for-profit) care delivery, prohibitive routine working practices, and scarce resources for the psychosocial and relational aspects of care. Wider and organisational discourse conflicted with the care values of nursing home staff and residents which caused tensions in the care-giver/care-recipient role. Specifically in the nursing home context staff experienced conflict between their professional obligation to meet the physical care needs of residents, and their vocational desire to care deeply for residents at the relational level. Staff also resented rationalised care at organisational level that reflected wider discourses of care work and older people as undervalued, and felt their contribution to the nursing home community was not recognised or rewarded by the nursing home hierarchy.

For most residents the nursing home represented loss and their ability to regain a sense of control over their increasingly powerless lives was thwarted by

the nursing home and staffs' embodiment, and enactment, of the aforementioned triage of disempowering discourses: namely medical, rationalised and risk-averse. Residents were better able to negotiate their new identity as a member of the nursing home community if they had social and/or practical support beyond the nursing home; found at least one positive and sustained relationship within the nursing home; felt believed by staff, other residents and family; and became more institutionalised i.e., accepted and ceased from resisting the rules of the nursing home community. In effect, residents were only able to fully integrate into nursing home life by relinquishing control and adopting a role that was socially acceptable to other nursing home dwellers. Both staff and residents were ill equipped to deal with the numerous conflicts they negotiated, and it is evident that little if anything is in place (either culturally, morally, or practically) to support them in their individual and yet inextricably linked care-giver/care-recipient roles.

The conclusion I must draw here is that despite the individual care values of participating nursing home staff being aligned with the relationship-centred care values of nursing home residents, it is unlikely that dignity conserving care can thrive in nursing homes that themselves reside in an 'impoverished' environment where the cultural values continue to depict old age as incapacity and a burden, and care work as menial and undervalued. In order to build a caring space that older people in need of care can truly call their 'home' these fundamental values must first be addressed, as the cultural values are the foundations on which a community is built. The findings of this thesis and more recent literature (eg., Gallagher, 2017; and Gilbert et. al., 2021) reflect the 'Western' ethic of care described by Joan Tronto over thirty years ago: one that undervalues older people and care work. These findings are an indicator that very little has changed in terms of values, attitudes and behaviours relating to care of

older people in society, and nor will it without intervention. I would argue that present findings of the undervaluing of older people and care work at macro level, particularly in the social care context have been reflected in the failure to respond to the needs of staff, residents and their families throughout the Covid 19 pandemic (2020/2021) that prevailed in the latter stages of writing this thesis. In conclusion, for abuse and neglect of nursing care home residents to desist and quality care to thrive, we must first instil both nationally and globally a culture that values older people and social care work, and commits to and invests in resources that promote a relationship-centred ethic of care.

## References

- Abbott, K.M., Bangerter, L.R., Humes, S., Klumpp, R., & Van Haitsam, K. (2018) "It's important, but...": Perceived Barriers and situational dependencies to social contact preferences of nursing home residents. *The Gerontologist*, 58(6), 112601135. <https://doi.org/10.1093/geront/gnx109>
- Acker, G. (1999). *The realities of teachers' work*: London Cassell.
- Adelman, R.D., Greene, M.G., & Charon, R. (1991) Issues in physician-elderly patient interaction. *Ageing and Society*, 11, 127-148.
- Adra, M. G., Hopton, J., & Keady, J. (2015). Constructing the meaning of quality of life for residents in care homes in the Lebanon: Perspectives of residents, staff and family. *International Journal of Older People Nursing*, 10(4), 306–318. <https://doi.org/10.1111/opn.12094>
- Adland A.K., Gripsrud, B.H., Lavik, M.H., & Ramvi, E. (2021) "They Stay With You": Nursing Home Staff's Emotional Experiences of being in a close relationship with a resident in long-term care who died. *Journal of Holistic Nursing* (0)1-15. Accessed online on 16 September, 2021 at <https://journals.sagepub.com/doi/10.1177/08980101211017766>
- Age UK (2019) *Paying for residential care*. Accessed on 21<sup>st</sup> June, 2019 at <https://www.ageuk.org.uk/information-advice/care/paying-for-care/paying-for-a-care-home/>
- Akerström, M. (2002) Slaps, Punches, Pinches – But not Violence: Boundary-Work in Nursing Homes for the Elderly. *Symbolic Interaction*, 25(4), 515-536. <https://doi.org/10.1525/si.2002.25.4.515>
- Althusser, L. (1971) 'Ideology and ideological state apparatuses' in *Lenin and philosophy*. London, New Left Books. In M. Wetherell, S. Taylor, & S.J. Yates (Eds.) (2008) *Discourse as data: A guide for analysis*, p233. London, Sage.

- Altschuler, J. (2001) Meaning and centrality and caring activities among older women. *Journal of Women & Ageing*, 13, 79-100. In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.
- Alvesson, M., & Sköglberg, K. (2000[]). *Reflexive methodology: New vistas for qualitative research*. London, SAGE.
- Alzheimer's Society (2003) Wakefield and five towns young onset dementia project final report ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)) (p.192). In J. Burr & P. Nicolson (Ed.) (2005), *Researching health care consumers: Critical approaches*. London, Palgrave MacMillan.
- Antaki, C., Finlay, W. M. L., & Walton, C. (2007). The staff are your friends: Intellectually disabled identities in official discourse and interactional practice. *British Journal of Social Psychology*, 46(1), 1-18.
- Archer M., Bhaskar, R., Collier, A., Lawson, T., & Norrie, A. (1998) (Eds) *Critical Realism*. London, Routledge.
- Aventuro, B., (1991) *The meaning of care to geriatric persons living in a long-term care institution*. Doctoral Dissertation, New York University, NY.
- Baille, L. (2009) Patient dignity in an acute hospital setting: A case study. *International Journal of Nursing Studies*, 46(1), 23-37.
- Baillon, S., Scothern, G., Neville, P.G., & Boyle, A. (2006) Factors that contribute to stress in care staff in residential homes for the elderly. *Geriatric Psychiatry*, 11, 219-226.
- Bagnoli, A. (2009) Beyond the standard interview. The use of graphic elicitation and arts-based methods. *Qualitative Research*, 9, 547-570
- Baglay, H., Cordingley, L., Burns, A., Mosley, C.G., Sutcliffe, C., Challis, D. et al. (2000) Recognition of depression by staff in nursing and residential homes. *Journal of Clinical Nursing*, 9, 445-450. In M.T.McCabe, T. Davison, D. Mellor, & K. George (2009) Barriers to care for depressed older people: Perceptions of age care among medical professionals. *International Journal of Aging and Human Development*, 68(1), 53-64.

- Banaszak-Holl, J., & Hines, M.A. (1996) Factors associated with nursing home staff turnover. *The Gerontologist*, 36(4), 512-517.
- Bangerter, L. R., Van Haitsma, K., Heid, A. R., & Abbott, K. (2016). "Make me feel at ease and at home": Differential care preferences of nursing home residents. *The Gerontologist*, 56(4), 702–713.  
<https://doi.org/10.1093/geront/gnv026>
- Barrowclough, C., Haddock, G., Lowens, I., Connor, A., Pidliswyj, J., & Tracey, N. (2001) Staff expressed emotion and causal attributions for client problems on a low security unit: An exploratory study. *Schizophrenia Bulletin*, 27 (3), 517-526.
- Bayer, T., Tadd W., & Krajcik S. (2005) "Dignity: The voice of older people":22-29. *Quality in Ageing and Older Adults*, 6(1):22-29.  
<https://doi.org/10.1108/14717794200500005>
- BBC News (23 June) (2012) *Care home whistle-blowers increasing*. Accessed online on 27<sup>th</sup> May, 2019 at <https://www.bbc.co.uk/news/health-18563885>
- BBC News (April, 2014) *Report on the Panorama Documentary of the Od Deanery care home*. Accessed online on 18<sup>th</sup> June, 2019 at <https://www.bbc.co.uk/news/av/uk-27217218/care-home-abuse-staff-sacked-or-suspended-over-poor-care>
- Beckford, M. (2011, 06 December) Southern Cross care home collapse could happen again, MP's warn. *The Telegraph*. Retrieved May 1, 2012, from [www.telegraph.co.uk](http://www.telegraph.co.uk)
- Bell, S. (2002). Photo images: Jo Spence's narratives of living with illness. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6, 5-30.
- Bento, R.F. (1994) "When the show must go on". *Journal of Managerial Psychology*, 9(6), 35-44.
- Berdes, C., & Eckert, J. M. (2007). The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.

- Beresford, P. (2010) *Funding social care: what service users say*. Joseph Rowntree Foundation, ref: 2486.
- Bergener, S.C., Jirovec, M., Murrell, L., & Barton, D. (1992) Caregiver and environmental variables related to difficult behaviours in institutionalised demented elderly persons. *Journal of Gerontology: Psychological Sciences*, 47, 242-249. In M.T. McCabe, T. Davison, D. Mellor, & K. George (2009) Barriers to care for depressed older people: Perceptions of age care among medical professionals. *International Journal of Aging and Human Development*, 68(1), 53-64.
- Berland, G (2007) The view from the other side – patients, doctors and the power of a camera. *New England Journal of Medicine*, December, 2533-2536.
- Bernstein, R. (1994) "Foucault: Critique as a philosophical ethos". In *Critique and power: Recasting the Foucault/Habermas Debate*, (ed.) M Kelly. Cambridge, Mass: The MIT Press. Cited in C. Hendricks (online) Foucault's prophesy: The intellectual as exile. Accessed online on 25.02.2014 at <http://www.manitowoc.uwc.edu/staff/awhite/christ00.htm>
- Berry, D. (2006) *Health Communication: Theory and Practice*. Berkshire, New York: Open University Press.
- Betio, F., Simonazz, A., & Villa, P. (2006) Change in care regimes and female migration: The "care drain" in the Mediterranean. *Journal of European Social Policy*, 16, 271-285. In R. Rodrigues, & A., Schmidt, (2010) Expenditures for long-term care: At the crossroads between family and state. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 23(4), 183-193.
- Bhaskar, R. (1975a) *A Realist Theory of Science [RTS]*, Leeds: Leeds Books.
- Bhaskar, R. (1975b) *The possibility of naturalism*. Hemel Hempstead: Harvester, Wheatsheaf.
- Bhaskar, R., & Lawson, T. (1998) Introduction: basic texts and developments. In M. Archer et al. (eds), *Critical Realism* (pp. 3-15). London, Routledge.

Billig, M. (2011) Writing social psychology: Fictional things and unpopulated texts. *British Journal of Social Psychology*, 50, 4-20.

Boelsma, F., Baur, V. E., Woelders, S., & Abma, T. A. (2014). "Small" things matter: Residents' involvement in practice improvements in long-term care facilities. *Journal of Aging Studies*, 31, 45–53.  
<https://doi.org/10.1016/j.jaging.2014.08.003>

Bolin, K., Kindgren, B., & Lundborg, P. (2008) Your next of kin or your own career? Caring and working among the 50+ of Europe. *Journal of Health Economics*, 27, 718-738. In R. Rodrigues, & A., Schmidt, (2010) Expenditures for long-term care: At the crossroads between family and state. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 23(4), 183-193.

Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nursing Ethics*, 23(2), 142–153.  
<https://doi.org/10.1177/0969733014557719>

Bourbonnais, A., & Ducharme, F. (2010). The meanings of screams in older people living with dementia in a nursing home. *International Psychogeriatrics*, 22(7), 1172-1184.

Braun, V. & Clarke, V. (2006) *Using thematic analysis in psychology*. *Qualitative Research in Psychology*, 3 (2). pp. 77-101. ISSN 1478-0887.

Brewer, R (2007) *Your PhD thesis: How to plan, draft, revise and edit your thesis*. Studymates Ltd., United Kingdom.

British Psychological Society (BPS) Code of Ethics and Conduct (2009) *Guidance published by the ethics committee of the British Psychological Society*. The British Psychological Society, Leicester. ISBN: 978-1-85433-495-4.

Brodsky, H., Draper, B., & Low, L.F. (2003) Nursing home staff attitudes towards residents with dementia: Strain and satisfaction with work. *Journal of Advanced Nursing*, 44, 583-590.



- Brooker, D. (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13, 1-8 doi:10.1017/S095925980400108X
- Brown, E.L., McAvay, G., Raue, P.J., Moses, S., & Bruce, M.L. (2003) Recognition of depression among elderly recipients of home care services. *Journal of Advanced Nursing*, 44, 583-590.
- Brown, E.L., Bruce, M.L., McAvay, G.J, Raue, P.J., Lachs, M.S. & Nassisi, P. (2004) Recognition of late-life depression in home care: Accuracy of the outcome and assessment information set. *Journal of American Geriatrics Society*, 52(6), 995-999. In M.T.McCabe, T. Davison, D. Mellor, & K. George (2009) Barriers to care for depressed older people: Perceptions of age care among medical professionals. *International Journal of Aging and Human Development*, 68(1), 53-64.
- Brown, P.R. (2008) Trusting in the new NHS: Instrumental versus communicative action. *Sociology of Health and Illness*, 30(3), 349-363.
- Brown-Wilson, C. (2008) Using relationships to develop practice that values the contribution of older people, families and staff. *International Journal of Older People Nursing* 3, 274-277.
- Brown-Wilson, C., Swarbrick, C., Pilling, M., and Keady, J. (2012) The senses in practice: enhancing the quality of care for residents with dementia in care homes. *Journal of Advanced Nursing*, 69(1), 77-90.
- Bruner, J. (1990) *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Burgio, L.D., Fisher, S.E., Fisher, K., Fairchild, J., Scilley, K., & Hardin, J.M. (2004) Quality of care in the nursing home: Effects of staff assignment and work shift. *The Gerontologist*, 44(3), 368-377.
- Burr, J. (2005) On the shoulder of giants': Putting the quality into qualitative methods in 'consumer' research. In J. Burr & P. Nicolson (Ed.), *Researching health care consumers: Critical approaches*, (pp. 112-128). Palgrave Macmillan.
- Bury, M. (1991) The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness*, 13, 451-468.

- Bury, M. (1998) Postmodernity and Health, 1-28 in G., Scrambler & P., Higgs (eds) *Modernity, Medicine and Health*. London: Routledge.
- Campbell, D., & Meikle, J. (2011, October) Half of NHS hospitals fail to care for elderly. *The Guardian*. Retrieved May 2, 2012, from <http://www.guardian.co.uk/society/2011/oct/13/nhs-hospitals-care-of-elderly>
- Carabine, J. (2008) *A genealogical analysis*. In M. Wetherell, S. Talyor, & S.J. Yates (Eds.), *Discourse as data: A guide for analysis*, (pp. 267-310). London, Sage.
- Care Quality Commission (CQC) Regulations (2009) *Guidance about compliance with health and social care act, 2008: Care home services with nursing (CHN)*. Retrieved on May 2, 2012 from <http://www.guidanceaboutcompliance.org.uk/step4-landing.php>
- Care Quality Commission (CQC) (2011) (a) The state of health care and social adult care in England: An overview of key themes in care in 2010/11.
- Care Quality Commission (CQC) (2011b). *Review of compliance for Orchid View Nursing Home conducted 29, July, 2011*. Accessed online on 20.02.2014 at <http://www.cqc.org.uk/directory/1-131738204>
- Care Quality Commission (CQC) (December) (2011)(c): *Raising a concern with CQC: A quick guide for health and care staff about whistleblowing*. Accessed online on 18<sup>th</sup> June, 2019 at <https://www.cqc.org.uk/news/stories/quick-guide-raising-concern-about-your-workplace>
- Care Quality Commission (CQC) (November, 2013) *Whistleblowing: guidance for providers who are registered with the Care Quality Commission*. Accessed online on 18<sup>th</sup> June, 2019 at [https://www.cqc.org.uk/sites/default/files/documents/20131107\\_100495\\_v5\\_00\\_whistleblowing\\_guidance\\_for\\_providers\\_registered\\_with\\_cqc.pdf](https://www.cqc.org.uk/sites/default/files/documents/20131107_100495_v5_00_whistleblowing_guidance_for_providers_registered_with_cqc.pdf)
- Care Quality Commission (CQC) (March) (2014a) *Quality report from unannounced inspection of Old Deanery in February, 2014*. HoC. Accessed online on 18<sup>th</sup> June, 2019 at

[https://www.cqc.org.uk/sites/default/files/old\\_reports/1-121360985\\_The\\_Old\\_Deanery\\_Care\\_Home\\_INS1-1161103202\\_Responsive\\_-\\_Concerning\\_Info\\_01-04-2014.pdf](https://www.cqc.org.uk/sites/default/files/old_reports/1-121360985_The_Old_Deanery_Care_Home_INS1-1161103202_Responsive_-_Concerning_Info_01-04-2014.pdf)

Care Quality Commission (CQC) (August) (2014b) *Special measures: one year on A report into progress made at 11 NHS trusts that were put into special measures in July, 2013*. Accessed online on 18<sup>th</sup> June, 2019 at [https://www.cqc.org.uk/sites/default/files/20140801\\_special\\_measures\\_on\\_e\\_year\\_on\\_report\\_final.pdf](https://www.cqc.org.uk/sites/default/files/20140801_special_measures_on_e_year_on_report_final.pdf)

Care Quality Commission (CQC) (March) (2015) *Quality report from unannounced inspection of Old Deanery in November, 2014*. HoC. Accessed online on 18<sup>th</sup> June, 2019 at [https://www.cqc.org.uk/sites/default/files/new\\_reports/AAAB6392.pdf](https://www.cqc.org.uk/sites/default/files/new_reports/AAAB6392.pdf)

Care Quality Commission (CQC) (2017a) *The state of health care and adult social care in England: An overview of key themes 2016/17*. HoC. Accessed online on 17<sup>th</sup> June, 2019 at [https://www.cqc.org.uk/sites/default/files/20171123\\_stateofcare1617\\_report.pdf](https://www.cqc.org.uk/sites/default/files/20171123_stateofcare1617_report.pdf)

Care Quality Commission (CQC) (December) (2017b). *Whorlton Hall Quality Report* Accessed online on 26<sup>th</sup> May, 2019 at [https://www.cqc.org.uk/sites/default/files/new\\_reports/AAAG8679.pdf](https://www.cqc.org.uk/sites/default/files/new_reports/AAAG8679.pdf)

Care Quality Commission (CQC) (March) (2018a). *Whorlton Hall Quality Report*. Accessed on 26<sup>th</sup> May, 2019 at [https://www.cqc.org.uk/sites/default/files/new\\_reports/AAAH3380.pdf](https://www.cqc.org.uk/sites/default/files/new_reports/AAAH3380.pdf)

Care Quality Commission (CQC) (Oct) (2018b) *The state of health care and adult social care in England, 2017/18*. HoC. Accessed online on 18<sup>th</sup> June, 2019 at [https://www.cqc.org.uk/sites/default/files/20171011\\_stateofcare1718\\_report.pdf](https://www.cqc.org.uk/sites/default/files/20171011_stateofcare1718_report.pdf)

Care Quality Commission (CQC) (January) (2019) *Mulberry Court Inspection Report*. Accessed online on 18<sup>th</sup> June, 2019 at

[https://www.cqc.org.uk/sites/default/files/new\\_reports/INS2-5868607931.pdf](https://www.cqc.org.uk/sites/default/files/new_reports/INS2-5868607931.pdf)

- Care Services Efficiency Delivery (CSED) (2007) Demand forecasting and capacity planning: Anticipated future needs toolkit, version 1. Retrieved on May 02, 2012 from <http://www.csed.dh.gov.uk/SiteSearch/?page=doSearch&keywords=future+needs+toolkit&x=0&y=0>
- Carpenter, B.D., Kissel, E.C., & Lee, M.M. (2007) Preferences and life evaluations of older adults with and without dementia: Reliability, stability, and proxy knowledge. *Psychology and Aging*, 22(3), 650-655.
- Carpenter, I., & Stosz, L. (2008) *Developing the use of 'MDS-RAI' reports for UK care homes*. Joseph Rowntree Foundation. Retrieved on May 04, 2012 from [www.jrf.org.uk](http://www.jrf.org.uk)
- Castle, N.G. (2010) An instrument to measure job satisfaction of certified nurse assistants. *Applied Nursing Research*, 23, 214-220.
- Castle, N.G., Degenholtz, H., & Rosen, J. (2006) Determinants of staff job satisfaction of caregivers in two nursing homes in Pennsylvania. *BMC Health Services Research*, 6(60), 1-11.
- Catalini, C. & Minkler, M. (2010). Photovoice: A review of the literature in health and public health. *Health Education & Behaviour*, 37, 424-451.
- Cattan, M., & Guintoli, G. (2010) *Care and support for older people in Bradford: their perspectives, aspirations and experiences*. Joseph Rowntree Foundation. ISSN 0958-3084.
- Chamberlain, K., (2000). Methodolatry and qualitative health research. *Journal of Health Psychology*, 5, 285-296.
- Chan, H. Y. L., & Pang, S. M. C. (2007). Quality of life concerns and end-of-life care preferences of aged persons in long-term care facilities. *Journal of Clinical Nursing*, 16(11), 2158-2166.

- Chappell, N. L., Havens, B., Hollander, M. J., Miller, J. A., & McWilliam, C. (2004). Comparative costs of home care and residential care. *The Gerontologist*, 44(3), 389-389-400.
- Cho, E., Kim, H., Kim, J., Lee, K., Meghani, S. H., & Chang, S. J. (2017). Older adult residents' perceptions of daily lives in nursing homes. *Journal of Nursing Scholarship*, 49(5), 495–503. <https://doi.org/10.1111/jnu.12314>
- Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2004) Dignity in the terminally ill: An empirical model. *Social Science and Medicine*, 54(3):433-43.
- Chochinov, H.M. (2004) Dignity and the Eye of the Beholder. *Art of Oncology*, 22(7):1336-1340. DOI: 10.1200/JCO.2004.12.095
- Chochinov, H.M. (2005) Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, 23(24):5520-5. DOI:10.1200/JCO.2005.08.391
- Chochinov, H.M. (2007). Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. *British Medical Journal*, 335, 184-187.
- Chou, S., Boldy, D. P., & Lee, A. H. (2001). Measuring resident satisfaction in residential aged care. *The Gerontologist*, 41(5), 623-623-31.
- Clare, L., & Cox, S. (2003) Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability and Society*, 18(7), 935-953.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An interpretative phenomenological analysis. *The Gerontologist*, 48(6), 711-711-20.
- Clark, P., & Bowling, A. (1990). Quality of everyday life in long stay institutions for the elderly: An observational study of long stay hospital and nursing home care. *Social Science & Medicine*, 30(11), 1201-1210.
- Clarke, A., Hanson, E.J., Ross, H. (2003). Seeing the person behind the patient: Enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12, 697-706.

- Clark, A., Prosser, J., & Wiles, R. (2010). Ethical issues in image-based research. *Arts & Health*, 2(1), 81–93. doi:10.1080/17533010903495298
- Clarkson, P., Hughes, J., & Challis, D. (2005). The potential impact of changes in public funding for residential and nursing-home care in the United Kingdom: The residential allowance. *Ageing and Society*, 25(2), 159-159-180.
- Clouston S.A.P., Brewster, P., Kuh, D., Richards, M., Cooper, R., Hardy, R., Rubin, M.S., & Hofer, S.M. (2013) *Epidemiologic Reviews*, 35(1): 33-50. Accessed online on 28<sup>th</sup> April, 2019 at <https://academic.oup.com/epirev/article/35/1/33/551021>
- Cohen, M. A. (1998). Emerging trends in the finance and delivery of long-term care: Public and private opportunities and challenges. *The Gerontologist*, 38(1), 80-80-9.
- Cohen-Mansfield, J. (1995) Stress in nursing home staff: A review and theoretical model. *Journal of Applied Gerontology*, 14(4), 444-466. <http://dx.doi.org/10.1177/073346489501400406>
- Cohen-Mansfield, J., & Wirtz, P. W. (2009). The reasons for nursing home entry in an adult day care population: Caregiver reports versus regression results. *Journal of Geriatric Psychiatry and Neurology*, 22(4), 274-281.
- Cohen-Mansfield, J., Shmotkin, D., Blumstein, Z., Shorek, A., Eyal, N., Hazan, H., and CALAS Team (2013) The old, old-old, and the oldest old: continuation or distinct categories: An examination of the relationship between age and changes in health, function, and wellbeing. *International Journal of Aging and Human Development* 77(1):37-57. doi:10.2190/AG77.1.c
- Community Care Bulletin (2002) ISBN 1 84182 542 5 Crown Copyright, Sept, 2002, 1-32.
- Conn, D.K., & Kaye, A. (2007) The suicidal resident. In D.K.Conn, N. Herrmann, A. Kaye, D. Rewilak, & B. Schoght (Eds.) Practical psychiatry in the long-term care home: A handbook for staff. Cambridge, MA: Hogrefe & Huber. In N.S. Reiss, & C.L.Tishler, (2008b). Suicidality in nursing home

residents: Part II. Special issues. *Professional Psychology: Research and Practice*, 39(3), 271-275.

Conner, M., & Norman, P. (Eds.). (2008) *Predicting health behaviour*. Open University Press.

Connolly, S., & O'Reilly, D. (2009). Variation in care home admission across areas of Northern Ireland. *Age and Ageing*, 38(4), 461-461-465.

Conroy, J. (2006) Knowledge driven practice in care homes. *Journal of Dementia Care*, 14(4), 26-9.

Conroy, J. (2008) Increasing knowledge: can it improve practice? *Journal of Dementia Care*, November/December, 30-34.

Coward, R.T., Hogan, T.L., Duncan, R.P. Horne, C.H., Hilker, M.A., & Felsen, L.M. (1995) Job satisfaction of nurses employed in rural and urban long-term facilities. *Research in Nursing and Health*, 18(3), 271-284. In N.G. Castle, H. Degenholtz, and J. Rosen (2006) Determinants of staff job satisfaction of caregivers in two nursing homes in Pennsylvania. *BMC Health Services Research*, 6(60), 1-11.

Craig, C. (2017) Imagined futures: designing future environments for the care of older people. *The Design Journal*, 20 (Sup 1), S2336-S2347 Available from Sheffield Hallam University Research Archive (SHURA) at: <http://shura.shu.ac.uk/16701/>

Crilly, N., Blackwell, A., & Clarkson, P. (2006). Graphic elicitation: Using research diagrams as interview stimuli. *Qualitative Research*, 6, 341-366.

Cromby, J. (2007) Toward a psychology of feeling. *International Journal of Critical Psychology*, 21, 94-118.

Cromby, J. (2011) Affecting qualitative Health Psychology. *Health Psychology Review*, 5(1), 79-96.

Cromby, J. (2012) Beyond belief. *Journal of Health Psychology* (online), 1-15. DOI: 10.1177/1359105312448866

- Crossley, M.L. (2000) *Introducing narrative psychology: The self and the construction of meaning*. Buckingham. Open University Press.
- Crossley, M.L. (2010). *Health Psychology; Rethinking health psychology*. Open University Press.
- Crotty, M. (1985) Communication between nurses and their patients. *Nurse Education Today*, 5, 130-134.
- Crotty, M. (2009). *The foundations of social research: Meaning and perspective in the research process*. London Sage.
- Cunningham L., Kennedy, J., Nwolisa, F., Callard, L., & Wike, C. (2012): Patients Not Paperwork: Bureaucracy affecting nurses in the NHS. *Institute for Innovation and Improvement*. Accessed on 24<sup>th</sup> July, 2019 at <https://www.qualitasconsortium.com/index.cfm/reference-material/fundamentals/patients-not-paperwork/>
- Data Protection Act (1998) Crown Copyright. Accessed online on 25.02.2014 at <https://www.legislation.gov.uk/ukpga/1998/29/introduction>
- Davies, S. (2001) The care needs of older people and family caregivers in continuing care settings. In: Nolan, M., Davies, S. and Grant, G. (eds) *Working with older people and their families: key issues in policy and practice*. Open University Press, Buckingham, pp 75-98.
- Davies, S., & Brown Wilson, C. (2007) Creating a sense of community. In *National Care Homes Research and Development (NCHR&D) forum 'My Home Life: Quality of life in care homes: A review of the literature*. Help the Aged, London. Retrieved on 15, May, 2012 from [http://www.ageuk.org.uk/search1/?keyword=davies+and+brown+wilson+2007&nation=ageuk\\_en-GB](http://www.ageuk.org.uk/search1/?keyword=davies+and+brown+wilson+2007&nation=ageuk_en-GB)
- Davies, S., & Nolan, M. (2004). 'Making the move': Relatives' experiences of the transition to a care home. *Health and Social Care in the Community*, 12(6), 517-517-526.
- Department of Health (DOH) (1989) *Working for patients*. Cmnd 555. London: HMSO.



Department of Health (DOH) (1991) *The patient's charter*. London:HMSO

Department of Health, (DOH) (2000) *National Health Service plan*. The Stationery Office. ISBN: 0101481837. Retrieved on May 03, 2012 from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4010198](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4010198)

Department of Health (DOH) (2001) *National Services Framework for Older People: Department of Health*. London: HMSO.

Department of Health (DOH) (2003) *NHS funded nursing care: Results of the November 2003 consensus of residents in care homes receiving nursing care in England*. Accessed on 21<sup>st</sup> June, 2019 at [https://webarchive.nationalarchives.gov.uk/20070703120000/http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalsocialcare/DH\\_4086810.html](https://webarchive.nationalarchives.gov.uk/20070703120000/http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalsocialcare/DH_4086810.html)

Department of Health (DOH) (2005) *Our Health, Our Care, Ours Say*. Retrieved on May 03, 2012 from [http://www.newhamwdtrial.org/user\\_files/downloads/DH\\_Our\\_Health\\_Our\\_Care\\_Our%20Say\\_BriefGuide.pdf](http://www.newhamwdtrial.org/user_files/downloads/DH_Our_Health_Our_Care_Our%20Say_BriefGuide.pdf)

Department of Health (DOH) (2009a) *Personal Care at Home Bill*. The Stationery Office, Crown copyright. Retrieved on May 03, 2012 from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH\\_109140](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_109140)

Department of Health (DOH) (2009b) *Living well with dementia: a National dementia strategy implementation plan*. The Stationery Office, Crown Copyright. Retrieved on May 03, 2012 from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103137](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103137)

Department of Health (DOH) (2010) *White Paper Equity and excellence: Liberating the NHS*. Crown copyright. HMSO. Retrieved on May 03, 2012 from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_118602](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_118602)

- Department of Health (DOH) (2013) *Report of the Mid Staffordshire NHS Foundation Trust public inquiry (Francis Report)*. London:HMSO.
- Department of Health and Social Security (DHSS) (1983) *NHS management inquiry (Griffiths report)*. London: HMSO.
- Dewing, J. (2004) Concerns relating to the application of frameworks to promote person-centredness in nursing with older people. *Journal of Clinical Nursing*, 13(1), 39-44 doi: 10.1111/j.1365-2702.2004.00925.x
- DiBiase, R.J. (2009) *Disenfranchised Grief: Nurses acknowledging and dealing with loss*. Presentation at the RN-AIM Fourth Annual Conference and Assembly, Plymouth. Accessed online on 17 September, 2014 at [http://www.rn-im.org/media/2009\\_annual\\_conf\\_matls\\_autogen/Disenfranchised Greif.pdf](http://www.rn-im.org/media/2009_annual_conf_matls_autogen/Disenfranchised_Greif.pdf)
- Dingwall, R., & Murray, T. (1983) Categorisation in accident departments: "Good" patients, "bad" patients and "children". *Sociology of Health and Illness*, 5(52), 127-48.
- Doise, W. (1986). *Levels of explanation in social psychology*. Cambridge, UK:Cambridge University Press.
- Doka, K.J. (Ed.) (1989) *Disenfranchised Grief: New directions, challenges and strategies for practice*. Illinois: Research Press.
- Donnelly, L., & MacEntee, M. I. (2016). Care perceptions among residents of LTC facilities purporting to offer person-centred care. *Canadian Journal on Aging*, 35(2), 149–160. <https://doi.org/10.1017/S0714980816000167>
- Draft Legislative Programme (DLP) (2007) *Preparing Britain for the future*. The Stationery Office, Crown copyright, 1-87. ISBN: 9780101737227. Retrieved on May 03, 2012 from <http://webarchive.nationalarchives.gov.uk/20100303153631/http://www.official-documents.gov.uk/document/cm73/7372/7372.pdf>

- Dudman, J. (2007) Context. In *National Care Homes Research and Development (NCHR&D) forum 'My Home Life: Quality of life in care homes: A review of the literature*. Help the Aged, London. 11-23.
- Dunn, H.D. & Moore, T.J. (2014) 'You can't be forcing food down 'em': Nursing home carers' perceptions of residents' dining needs. *Journal of Health Psychology* 21(5):619-27 doi: 10.1177/1359105314532971
- Dybvik, T. K., Gjengedal, E., & Lykkeslet, E. (2014). At the mercy of others—For better or worse. *Scandinavian Journal of Caring Sciences*, 28(3), 537–543. <https://doi.org/10.1111/scs.12078>
- Eborall, C., & Griffiths, D. (2008) *Skills for Care: The state of adult social care workforce in England. The third report of Skills for Care's Skills Research and Intelligence Unit*. Leeds: Skills for Care
- Edwards, D., Ashmore, M., & Potter, J. (1995) Death and furniture: The rhetoric, politics and theology of bottom- line arguments against relativism. *History of the Human Sciences*, 8(2), 25-49.
- Emmison, M. (2004) The conceptualisation and analysis of visual data. In D.Silverman, (Ed.) *Qualitative research: Theory method and practice* (pp. 246-265), London, Sage.
- Equality Act (2010). Retrieved on 18, May, 2012 from Legislation.gov.uk. [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)
- Equality and Equal Rights Commission (2011) *Close to home: Inquiry into older people and human rights in home care*. Retrieved on May 02, 2012 from EERC [http://www.equalityhumanrights.com/uploaded\\_files/homecareFI/home\\_care\\_report.pdf](http://www.equalityhumanrights.com/uploaded_files/homecareFI/home_care_report.pdf)
- Ewbank, L., Thompson, J., & McKenna, H. (2017) *NHS hospital bed numbers: past, present, future*. The Kings Fund. accessed on 17<sup>th</sup> June, 2019 at <https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers>

- Fenig, S., Levav, I., Kohn, R., Yelin, N. (1993) Telephone vs face-to-face interviewing in a community psychiatric survey. *American Journal of Public Health* 83(6): 896-898 <https://doi.org/10.2105/AJPH.83.6.898>
- Felton, J.S. (1998) Burnout as a clinical entity: Its importance in health care workers. *Occupational Medicine*, 48(4), 237-250. Retrieved on May 03, 2012 from OXFORD JOURNALS <http://occmed.oxfordjournals.org/content/48/4/237.short>
- Flick U. (2007) *Qualitative research: A handbook*. Sage.
- Flick, U. (2009) *An introduction to qualitative research*. Sage.
- Flick, U., Garms-Homolová, V., & Röhsch, G. (2010). Sleep disorders and activities in long term care facilities – a vicious cycle? *Journal of Health Psychology*, 15(5), 744-754. Doi: 10.1177/1359105310368185.
- Forder, J., & Fernandez, J.L. (2011) *Length of stay in care homes*, report commissioned by Bupa Care Services, PSSRU Discussion Paper 2769, Canterbury: PSSRU
- Foucault, M. (1963) *The birth of the clinic*. London, Routledge.
- Foucault, M. (1972) *The Archaeology of Knowledge*. London, Tavistock. In G. Kendall, G., & G. Wickham (1999) *Using Foucault's methods*. London, Sage.
- Foucault, M. (1977) *Discipline and Punish: The Birth of the Prison*. London, Allen Lane. In G. Kendall, G., & G. Wickham (1999) *Using Foucault's methods*. London, Sage.
- Foucault, M. (1982) The subject and power. In H.L. Dreyfus & P Rabinow (Ed.), *Beyond structuralism and hermeneutics* (pp. 208-226). New York, Harvester Wheatsheaf.
- Foucault, M. (1997) Ethics: Subjectivity and truth. In R. Rabinow (Ed.), *The essential works of Foucault, 1954-1984 vol 1*, (pp. 334). New York, The New Press.

- Francis Report (2013) *Report of the Mid Staffordshire NHS foundation trust public inquiry*. HMSO. ISBN: 9780102981476
- Franklin, L.L., Ternestedt, B.M., & Nordenfelt, L. (2006) Views on dignity of Elderly Nursing Home Residents. *Nursing Ethics*, 13(2): 130-146  
<https://doi.org/10.1191/0969733006ne851oa>
- Fulton, J. (1996). Nursing: Biopsychosocial care? In N. Cooper, C. Stevenson, and G. Hale (Eds), *Integrating perspectives on health*. Buckingham: Open University Press.
- Gale, J. (1992) When research interviews are more therapeutic than therapy interviews. *The Qualitative Report*, 1(4) 1-4  
<https://doi.org/10.46743/2160-3715/1992.2036>
- Galiana, L., Tomas, .M., Fernandez, I., & Oliver, A. (2020) Predicting Well-Being among the elderly: The role of coping strategies. *Frontiers in Psychology*, 11, 616 <https://doi.org/10.3389/fpsyg.2020.00616>
- Gallagher, A., Curtis, K., Dunn, M., Baille, L. (2017) Realising dignity in care home practice: and action research project. *International Journal of Older People Nursing*. 12, 121-128 <https://doi.org/10.1111/opn.12128>
- Gallagher, A., Li, S., Wainwright, P., Jones, I.R., & Lee, D. (2008) Dignity in the care of older people – a review of the theoretical and empirical literature. *BMC Nursing*, 7(11), 1-12.
- Gamiel, T., & Hazan, H. (2006). The meaning of stigma: Identity construction in two old-age institutions. *Ageing & Society*, 26, 355-371.
- Gaugler, J.E., Hepburn, K., Mittleman S.M., & Newcomer, R. (2009). Predictors of change in caregiver burden and depressive symptoms following nursing home admission. *Psychology and Ageing* 24(2), 385–396.
- Gergen, K.J., & Gergen, M.M. (1986) Narrative form and the construction of psychological science. In T.R. Sarbin (Ed.), *Narrative Psychology* (pp. 22-44) Praeger, New York.
- Gieryn, T.G. (1983) Boundary-work and the demarcation of science from non-science. *Strains and interests in professional ideologies of scientists*.

- American Sociological Review, 48, 781-795. In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.
- Gieryn, T.G. (1995) Boundaries of science. In S. Jasanoff (Ed.), Handbook of science and technology studies (pp. 393-443). In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.
- Gieryn, T.F. (1999) Cultural boundaries of science: Credibility on the line. Chicago, University of Chicago Press. In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.
- Gilbert, A.W., Garratt, S.M., Kosowicz L., Ostaszkievicz J., and Dow, B. (2021) Aged Care Residents' Perspectives on Quality of Care in Care Homes: A Systematic Review of Qualitative Evidence. *Research on Aging*, 1-17, DOI: 10.1177/0164027521989074 Accessed on 15 August, 2021 at <https://journals.sagepub.com/doi/full/10.1177/0164027521989074>
- Goffman, E. (1961) Asylums: Essays on the social situation of mental patients and other inmates. Penguin.
- Goffman, E. (1971) *Relations in Public: Microstudies of the public order*. Basic Books, New York.
- Goodman, P. (2008) "It's just black, white, or Hispanic: An observational study of racialising moves in California's segregated prison reception centres. *Law & Society Review*, 42(4), 735-770.
- Grant, P.R. (1985) Who experiences the move into a nursing home as stressful? Examination of the relocation stress hypothesis using archival, time-series data. *Canadian Journal on Aging* 4(2), 87-100.
- Gubrium, J. (1995) Voice, context, and narrative in aging research. *Canadian Journal on Aging*, 14(S1), 68-81. In G., Hubbard, M.G. Downs, & S. Tester (2003) Including older people with dementia in research: challenges and strategies. *Aging and Mental Health*, September, 7(5), 251-362.

- Gubrium, J.F., & Holstein, J.A. (1999) The nursing home as a discursive anchor for the ageing body. *Ageing and Society*, 19(5), 519-538.
- Häggström, E., Mamhidir, A., & Kihlgren, A. (2010). Caregivers' strong commitment to their relationship with older people. *International Journal of Nursing Practice*, 16(2), 99-105.
- Hall, S., (2013) The work of representation. In S.Hall, J., Evans, J., & S. Nixon (Eds) *Representation: Cultural Representations and Signifying Practices*, pp. 13-74. London, Sage.
- Hall, S., Longhurst, S., & Higginson I.J. (2009) Living and dying with dignity: A qualitative study of the views of older people in nursing homes. *Age and Ageing* 38(4):411-6 doi: [10.1093/ageing/afp069](https://doi.org/10.1093/ageing/afp069)
- Hardey, M. (1998) *The social context of health*. Buckingham: Open University Press.
- Harmer, B. J., & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health*, 12(5), 548-558.
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17, 13-26.
- Harris\_Kojetin, L., Lipson, D., Fielding, J., Kiefer, K., & Stone, R.I. (2004) Recent findings on frontline long-term care workers: a research synthesis 1999-2003. DHHS/ASPE Office of Disability, Ageing and Long-Term Care Policy. In N.G. Castle, H. Degenholtz, and J. Rosen (2006) Determinants of staff job satisfaction of caregivers in two nursing homes in Pennsylvania. *BMC Health Services Research*, 6(60), 1-11.
- Harrison, J., & Frampton, S. (2017). Resident-centered care in 10 U.S. nursing homes: Residents' perspectives. *Journal of Nursing Scholarship*, 49(1), 6–14. <https://doi.org/10.1111/jnu.12247>



- Hasegawa, N., & Ota, K. (2019). Concept synthesis of dignity in care for elderly facility residents. *Nursing Ethics*, 26(7–8), 2016–2034. <https://doi.org/10.1177/0969733018824763>
- Haslam, C., Haslam, S. A., Jetten, J., Bevins, A., Ravenscroft, S., & Tonks, J. (2010). The social treatment: The benefits of group interventions in residential care settings. *Psychology and Aging*, 25(1), 157-167.
- Hatch, L.R. (2005) Ageism in the New Millennium: Gender and ageism. *Generations. American Society on Aging*. Accessed online on 25.02.2014 at <http://generations.metapress.com/content/vu2119541nv3/?p=3bf406b4d7e544b78496c69db85ddcd8&pi=0>
- Hauge, M., & Ory, M. (1987) Issues in elderly patient-provider interactions. *Research on Ageing*, 9, 3-44. In: R.D. Adelman, M.G. Greene, & R. Charon (1991) Issues in physician-elderly patient interaction. *Ageing and Society*, 11, 127-148.
- Heid, A. R., Eshraghi, K., Duntzee, C. I., Abbott, K., Curyto, K., & Van Haitsma, K. (2016). "It Depends": Reasons why nursing home residents change their minds about care preferences. *The Gerontologist*, 56(2), 243–255. <https://doi.org/10.1093/geront/gnu040>
- Heliker, D. (2007). Story sharing: Restoring the reciprocity of caring in long-term care. *Journal of Psychosocial Nursing and Mental Health Services*, 45(7), 20-23.
- Health Act (1999) *Part 1 The National Health Service*. The Stationery Office, 1-115. Retrieved on May 03, 2012 from DOH [http://www.legislation.gov.uk/ukpga/1999/8/pdfs/ukpga\\_19990008\\_en.pdf](http://www.legislation.gov.uk/ukpga/1999/8/pdfs/ukpga_19990008_en.pdf)
- Health and Safety at Work Act (1974) HMSO. Accessed online on 25.02.2014 at <http://www.legislation.gov.uk/ukpga/1974/37/contents>
- Health and Social Care Bill (2000) *Part 1 The National Health Service*. The Stationery Office. Retrieved on May 03, 2012 from



<http://www.parliament.the-stationery-office.co.uk/pa/cm200001/cmbills/009/2001009.htm>

Health and Social Care Bill (2008) *The governance of Britain: The government's draft legislative programme*. DOH. Retrieved on May 03, 2012 from <http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/HealthandSocialCareBill/index.htm>

Health and Social Care Act (2012) *The Stationery Office*: available online: accessed on 21st June, 2019 at [http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga\\_20120007\\_en.pdf](http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf)

Heijlenskjöld, B., Ekstedt, M., & Lindwall, L. (2010) The patient's dignity from the nurse's perspective. *Nursing Ethics*, 17, 313-324.

Heponiemi, T., Elovainio, M., Pekkarinen, L., Noro, A., Finne-Soveri, H. & Sinervo, T. (2006). The moderating effect of employee hostility on the association of long-term elderly care unit's negative resident characteristics to employee stress and well-being. *Journal of Occupational Health Psychology*, 11(2), 157-168.

Hinrichsen, G. (2008) Interpersonal psychotherapy as a treatment for depression in later life. *Professional Psychology: Research and Practice*, 39(3), 306-312.

Hinrichsen, G. (2010) Public policy and the provision of psychological services to older adults. *Professional Psychology: Research and Practice*, 41(2), 97-103.

Hinrichsen, G.A., & Emery, E.E., (2005) Interpersonal factors and late-life depression. *Clinical Psychology: Science and Practice*, 12, 264-275.

Hirsch, D. (2005) *Facing the cost of long-term care: Towards a sustainable funding system*. Joseph Rowntree Foundation, 1-46. Retrieved on May 02, 2012 from <http://www.jrf.org.uk/sites/files/jrf/1859353894.pdf>

Hirsch, D., & Spiers, P. (2010) Funding care: how can each generation pay its fair share? Joseph Rowntree Foundation, ref:2501.

- Hochschild, A. (1983) *The managed heart: The commercialisation of human feeling*. Berkley: University of California Press. In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.
- Hodgetts, D., Radley, A., Chamberlain, K., and Hodgetts, A. (2007). Health inequalities and homelessness: Considering material, spatial and relational dimensions. *Journal of Health Psychology*, 12, 709-725.
- Holland, J.M., Currier, J.M. & Gallagher-Thompson, D., (2009). Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. *Psychology and aging*, 24(1), 190-202.
- Howitt, D. (2010a) *Qualitative methods in psychology*. Pearson Education Ltd.
- Howitt, D. (2010b) Ethnography/participant observation. In *Introduction to qualitative research methods in psychology*, (pp. 111-134). Pearson Education Limited.
- Hubbard, G., Downs, M.G., & Tester, S. (2003) Including older people with dementia in research: challenges and strategies. *Ageing and Mental Health*, September, 7(5), 251-362.
- Institute of Public Care (IPC) (2010) *Oxfordshire county council: Support to the early intervention and prevention services for older people and vulnerable adults programme. Report on study pathways*. Retrieved on May 02, 2012 from IPC Publications <http://ipc.brookes.ac.uk/publications/index.php?kw=2721>
- Jacelon, C.S., & Henneman, E.A. (2004) Profiles in Dignity: Perspectives on nursing and critically ill older adults. *Critical Care Nurse*, 24, 30-35.
- Jacobson, N. (2007) Dignity and health: a review. *Social Science and Medicine*. 64(2): 292-302 DOI: [10.1016/j.socscimed.2006.08.039](https://doi.org/10.1016/j.socscimed.2006.08.039)
- Jacobson, N. (2009) A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*. 9:3 doi: 10.1186/1472-698X-9-3

- Jensen, C. (2008) Worlds of welfare services and transfers. *Journal of European Social Policy*, 18, 151-162. In R. Rodrigues, & A., Schmidt, (2010) Expenditures for long-term care: At the crossroads between family and state. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 23(4), 183-193.
- Johs-Artisensi, J. L., Hansen, K. E., & Olson, D. M. (2020). Qualitative analyses of nursing home residents' quality of life from multiple stakeholders' perspectives. *Quality of Life Research*, 29, 1229–1238. <https://doi.org/10.1007/s11136-019-02395-3>
- Jolanki, O. (2004) Moral argumentation in talk about health and old age. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*. 8(4), 483-503.
- Jones, P., Bunce, G., Evans, J., Bibbs, H., and Ricketts Hein, J. (2008). Exploring space and place with walking interviews. *Journal of Research Practice*, 4(2), Article D2. Retrieved on June 30, 2011 from JRP database <http://jrp.icaap.org/index.php/jrp/article/view/150/161>.
- Jongenelis, L., Pot, A.M., Eisses, A.M.H., Beekman, A.T.F., Kluiters, H., & Ribbe, M.W. (2004) Prevalence and risk indicators of depression in elderly nursing home patients: The AGED study. *Journal of Affective Disorders*, 83, 135-142. In N.S. Reiss, & C.L. Tishler, (2008a). Suicidality in nursing home residents: Part I. prevalence, risk factors, methods, assessment, and management. *Professional Psychology: Research and Practice*, 39(3), 264-270.
- Kadri, A., Rapaport, P., Livingston, G., Cooper, C., Robertson, S., & Higgs, P. (2018) Care workers, the unacknowledged persons in person-centred care: A secondary qualitative analysis of UK care home staff interviews. *PLoS ONE* 13(7): e0200031. <https://doi.org/10.1371/journal.pone.0200031>
- Kane, R.L., Bershadsky, B., Kane, R.A., Degenholtz, H.H., Liu, J., Giles, K., & Kling, K.C. (2004) Using Resident Reports of Quality of Life to Distinguish Among Nursing Homes. *The Gerontologist*, 44(5), 624-632.

- Kane, R.L. & Kane, R.A. (2005) Ageism in the New Millennium: Ageism in Healthcare and Long-Term Care. *Generations*. American Society on Aging. Accessed online on 25.02.2014 at <http://generations.metapress.com/content/vu2119541nv3/?p=3bf406b4d7e544b78496c69db85ddcd8&pi=0>
- Kang, B., Scales, K., McConnell, E. S., Song, Y., Lepore, M., & Corazzini, K. (2020). Nursing home residents' perspectives on their social relationships. *Journal of Clinical Nursing*, 29(7-8), 1162–1174. <https://doi.org/10.1111/jocn.15174>
- Kayser-Jones, J. (2003). Continuing to conduct research in nursing homes despite controversial findings: Reflections by a research scientist. *Qualitative Health Research*, 13, 114-128.
- Kellett, U. M. (1999). Searching for new possibilities to care: A qualitative analysis of family caring involvement in nursing homes. *Nursing Inquiry*, 6(1), 9-16.
- Kellett, U. (2007). Seizing possibilities for positive family caregiving in nursing homes. *Journal of Clinical Nursing*, 16(8), 1479-1487.
- Kendall, G., & Wickham, G. (1999) *Using Foucault's methods*. London, Sage.
- Kenyon, P. (Writer) & Chapman, M. (Director), (2011). *Undercover Care: The Abuse Exposed* [Panorama, special edition]. In Walsh, E, Byrne, M., & Plomin, J (Producers). BBC, United Kingdom.
- Keogh, B. (2013) *Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report*. Accessed online on 27<sup>th</sup> May, 2019 at <https://www.nhs.uk/nhsengland/bruce-keogh-review/documents/outcomes/keogh-review-final-report.pdf>
- Kerr, D., Wilkinson, H., & Cunningham, C. (2008). *Supporting older people in care homes at night*. Joseph Rowntree Foundation, York. Available to download at [www.crfr.ac.uk](http://www.crfr.ac.uk)

- Kerrison, S.H., & Pollok, A.M. (2001). Regulating Nursing Homes: Caring for older people in the private sector in England. *British Medical Journal*, 323:566-569.
- Kirkpatrick, M. & Brown, S. (2004). Narrative pedagogy: Teaching geriatric content with stories and the "Make a Difference" project. *Nursing Education Perspectives*, 25, 183-187.
- Kitwood, T. (1997) *Dementia reconsidered: the person comes first*. Open University Press.
- Klerman, G.L., Weissman, M.M., Rounsaville, B.J., & Chevron, E.S. (1984) Interpersonal psychotherapy of depression. Northvale, NJ:Jason Aronson. In G.A. Hinrichsen, (2008) Interpersonal psychotherapy as a treatment for depression in later life. *Professional Psychology: Research and Practice*, 39(3), 306-312.
- Kofod, J., & Birkemose, A. (2004) Meals in nursing homes. *Scandinavian Journal of Caring Science*, 18, 128-134.
- Kompter, A., (2001). Heirlooms, nikes and bribes: Towards a sociology of things. *Sociology*, 35(1), 59-75.
- Laing, W. (2002) *Calculating operating costs for care homes*. Joseph Rowntree Foundation. Accessed online on 17<sup>th</sup> June 2019 at <https://www.jrf.org.uk/report/calculating-operating-costs-care-homes>
- La Rue, A., & Watson, J. (1998). Psychological assessment of older adults. *Professional Psychology: Research and Practice*, 29(1), 5-14.
- Lawless, B., & Chen Y-W. (2019) Developing a Method of Critical Thematic Analysis for Qualitative Communication Inquiry. *Howard Journal of Communications*, 30(1):92-106.  
<https://doi.org/10.1080/10646175.2018.1439423>
- Laz, C. (2003) Age embodied. *Journal of Aging Studies*, 17, 503-519.
- Lazarus, R.S., Cohen, J.B., & Folkman, S. (1980) Psychological stress and adaptation: Some unresolved issues. In H. Seyle (Ed), *Seyles guide to stress research* (Vol. 1, 190-217). New York: Van Nostrand Reinhold. In

- J. Cohen-Mansfield, & P.W. Wirtz, (2009) The reasons for nursing home entry in an adult day care population: Caregiver reports versus regression results. *Journal of Geriatric Psychiatry and Neurology*, 22(4), 274-281.
- Lazarus, R.S. DeLongis, A., Folkman, S. & Gruen, R. (1985) Stress and adaptational outcome: The problem of confounded measures. *American Psychologist*, 40, 770-779. In J. Cohen-Mansfield, & P.W. Wirtz, (2009) The reasons for nursing home entry in an adult day care population: Caregiver reports versus regression results. *Journal of Geriatric Psychiatry and Neurology*, 22(4), 274-281.
- Lee, D. T. F., Woo, J., & Mackenzie, A. E. (2002). The cultural context of adjusting to nursing home life: Chinese elders' perspectives. *The Gerontologist*, 42(5), 667-667-75.
- Lee-Treweek, G. (2000). The insight of emotional danger: research experiences in a home for older people. In G. Lee-Treweek & S. Linkogle (Eds.) *Danger in the field: Risk and ethics in social research*. Routledge, London.
- Leutz, W. (2010-11). The changing face of long-term care and how a new immigrant workforce will shape its future. *Generations*, 34(4), 89-89-96.
- Levine, M. (1979) congress (and evaluators) ought to pay more attention to history. *American Journal of Community Psycholgy*, 7, 1-17. In W.R. Shadish, (1989) Private-sector care for chronically mentally ill individuals: The more things change the more they stay the same. *American Psychologist*, 44(8), 1142-47.
- Lieberman, M., & Tobin, S. (1983) The experience of old age: Stress, coping and survival (pp. 312-332). NY: Basic Books. In S. Sterns, & E. Kahana, (2007) Institutional constraints on residents in long-term care facilities for the elderly. *Research in the Sociology of Health Care*, 24:1-20.
- Lowenstein, J. (2008) The midnight meal and other essays about doctors, patients and medicine. New Haven, CT:Yale University Press. In J.

- Maben, J. Cornwell, & K. Sweeney (2010). In praise of compassion. *Journal of Research in Nursing*, 15(9), 9-13.
- Lyness, J.M., Cox, C., Curry, J., Conwell, Y., King, D.A., & Caine, E.D. (1995) Older age and the underreporting of depressive symptoms. *Journal of the American Geriatrics Society*, 43, 216-221. Abstract retrieved on 15, May, 2012 from PubMed <http://www.ncbi.nlm.nih.gov/pubmed/7884106>
- Maben, J., Latter, S., & Macleod-Clark, J. (2007) The challenges of maintaining ideals and standards in professional practice: evidence from a longitudinal qualitative study. *Nurse Inquiry*, 14, 99-113. In J. Maben, J. Cornwell, & K. Sweeney (2010). In praise of compassion. *Journal of Research in Nursing*, 15(9), 9-13.
- Maben, J., Cornwell, J., & Sweeney, K. (2010). In praise of compassion. *Journal of Research in Nursing* 15:9-13.
- MacRae, H.M. (1998) Women and caring: constructing self through others. *Journal of Women and Ageing*, 7(1-2), 145-167. In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.
- Maddox, G. L. (2003). Making a house a home. *The Gerontologist*, 43(6), 931-934.
- Marini, B. (1999) Institutionalised older adults' perceptions of nurse caring behaviours: a pilot study. *Journal of Gerontological Nursing*, 25, 10-16. Abstract retrieved on 20, May, 2014 from <http://europepmc.org/abstract/MED/10578760>
- Mauger, S., Deuchars, G., Sexton, S., & Schehrer, S. (2010) *Involving users in commissioning local services*. Joseph Rowntree Foundation, ref: 2482.
- Mayers, K. (1995) Storytelling: A method to increase discussion, facilitate rapport with residents and share knowledge among long-term care staff. *The Journal of Continuing Education in Nursing*, 26, 280-282.
- McCabe, M.P., Davison, T., Mellor, D., & George, K. (2009) Barriers to care for depressed older people: Perceptions of aged care among medical

professionals, *International Journal of Aging and Human Development*, 68(1),53-64.

McCloskey, R., & den Hoonaard, D. (2007) Nursing home residents in emergency departments: a Foucauldian analysis. *Journal of Advanced Nursing*, 59(2), 186-194.

McCormack, B. (2003) A conceptual framework for person-centred practice with older people: *Journal of Nursing Practice*. 9: 202-209

McCormack, B. (2004) Person-centredness in gerontological nursing: an overview of the literature. *International Journal of Older People in Nursing in association with Journal of Clinical Nursing*, 13(3), 31-38.

McCormack, B., & McCance, T.V. (2006) Development of a framework for person-centred nursing. *Journal of Advanced Nursing* 56(5), 472-479

McCormack, B., Dewing, J., & McCance, T. (2011) Developing person-centred care: Addressing contextual challenges through practice development. *The Online Journal of Issues in Nursing*, (31 May).

McIver, S. (2005) Listening to 'Quiet' voices. In J. Burr & P. Nicolson (Ed.), *Researching health care consumers: Critical approaches*, (pp. 180-199). Palgrave Macmillan.

McKenna, H., & Baird, B. (February, 2019) *Brexit and the implications for health and social care*. The Kings Fund. Accessed on 21<sup>st</sup> June, 2019 at <https://www.kingsfund.org.uk/publications/articles/brexit-implications-health-social-care>

McPherson, C.J., Wilson K.G., & Murray, M.A. (2007) Feeling like a burden: exploring the perspectives of patients at the end of life. *Social Science and Medicine*, 64(2):417-27 doi:10.1016/j.socscimed.2006.09.013

Melcher, J. (1988) Keeping our elderly out of institutions by putting them back in their homes. *American Psychologist*, 43(8), 643-647.

Mental Capacity Act (2005). Retrieved on 18, May, 2012 from legislation.gov.uk [http://www.legislation.gov.uk/ukpga/2007/12/pdfs/ukpga\\_20070012\\_en.pdf](http://www.legislation.gov.uk/ukpga/2007/12/pdfs/ukpga_20070012_en.pdf)



- Mental Capacity Act Code of Practice (2007) Sections 42 and 43 of Mental Capacity Act, 2005. *The Stationary Office*. Retrieved on May 02, 2012 from TSO  
[http://www.direct.gov.uk/prod\\_consum\\_dg/groups/dg\\_digitalassets/@dg/@en/@disabled/documents/digitalasset/dg\\_186484.pdf](http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/@disabled/documents/digitalasset/dg_186484.pdf)
- Merleau-Ponty, M. (1962) *Phenomenology of perception*. (C.Smith, Trans.) London, Routledge & Kegan Paul Ltd.
- ~~Mishler, E.G. (1986) *Research interviewing: Context and narrative*. Cambridge, MA, Harvard University Press.~~
- Mitchell, C. (2011) *Doing visual research*. Sage, London.
- Mitchell, G., & Agnelli, J. (2015) Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard* 30(7), 46-50.
- Moscovici, S. (1961) *Psychoanalysis, its image and its audience*. Paris, France: University Press
- Moyle, W., Fetherstonhaugh, D., Greben, M., & Beattie, E., & Aus-QoL group. (2015). Influencers on quality of life as reported by people living with dementia in long-term care: a descriptive exploratory approach. *BMC Geriatrics*, 15, 50. <https://doi.org/10.1186/s12877-015-0050-z>
- Moyle, W., Venturto, L., Griffiths, S., Grimbeek, P., McAllister, M., Oxlade, D., & Murfield, J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Aging and Mental Health*, 15(8), 970–977. <https://doi.org/10.1080/13607863.2011.583620>
- Murphy, F., Jones, S., Edwards, M., James, J., & Mayer, A (2009) The impact of nurse education on the caring behaviours of nursing students. *Nurse Education Today*, 29, 254-264. In J. Maben, J. Cornwell, & K. Sweeney (2010). In praise of compassion. *Journal of Research in Nursing*, 15(9), 9-13.
- Murphy, S., (Writer) (23 Nov 2018) *Companies running 'inadequate' UK care homes make £113m profit* [The Guardian]. Accessed online on 26<sup>th</sup> May,

2019 at <https://www.theguardian.com/society/2018/nov/23/revealed-companies-running-inadequate-uk-care-homes-make-113m-profit>

Murray, M. (1997) A narrative approach to health psychology: Background and potential. *Journal of Health Psychology*, 2, 9-20.

Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology*, 5, 337-347.

Murray, M.P. (Ed.). (2004). *Critical Health Psychology*. Palgrave Macmillan. ISBN 0- 333-99034 (pbk).

Naden, D., Rehnsfeldt, A., Raholm, M-B., Lindwall, L., Saspari, S., Aasgaard, T., Slettebo, S., Saeteren, B., Hoy, B., Lillesto, B., Heggstad, A.K.T., & Lohne, B. (2013) Aspects of indignity in nursing home residences as experienced by family caregivers. *Nursing Ethics*, 20(7), 748-761, doi:10.1177/0969733012475253

Nakrem, S., Vinsnes, A. G., Harkless, G. E., Paulsen, B., & Seim, A. (2013). Ambiguities: Residents' experience of 'nursing home as my home'. *International Journal of Older People Nursing*, 8(3), 216–225. <https://doi.org/10.1111/j.1748-3743.2012.00320.x>

Nakrem, S., Vinsnes, A. G., & Seim, A. (2011). Residents' experiences of interpersonal factors in nursing home care: A qualitative study. *International Journal of Nursing Studies*, 48(11), 1357–1366. <https://doi.org/10.1016/j.ijnurstu.2011.05.012>

National Audit of Dementia Care (2011) *Report of the National Audit of Dementia care in general hospitals*. Royal college of Psychiatrists' Centre for Quality Improvement, London, 1-242.

National Audit Office (Feb) (2018) *Department of Health & Social Care: The adult social care workforce in England*. Accessed online on 7<sup>th</sup> April, 2019 at <https://www.nao.org.uk/wp-content/uploads/2018/02/The-adult-social-care-workforce-in-England.pdf>

National Guardian's Office (September, 2018) *Speaking up in the NHS in England: A summary of speaking up to Freedom to Speak Up Guardians*

*in NHS trusts and foundation trusts*. Accessed online on 27<sup>th</sup> May, 2019 at <https://www.cqc.org.uk/sites/default/files/20180919%20-%20Speaking%20up%20data%20report%202017%20-18.pdf>

National Minimum Standards (NMS) (2002) *Care homes for older people: National minimum standards care homes regulations*. The Stationary Office.

National Statistics Online, (2011). Social trends population data 1971-2031. Office For National Statistics. Accessed online on 25.02.2014 at <http://www.ons.gov.uk/ons/taxonomy/search/index.html?nscl=Population+Estimates&nscl-orig=Population+Estimates&content-type=Dataset&content-type=Reference+table&sortDirection=DESCENDING>

NHS and Community Care Act (1990) Accessed on 10<sup>th</sup> June 2012 at <http://www.cavamh.org.uk/directories/mental-health-directory/legal-matters/the-national-health-service-and-community-care-act-1990>

NHS Digital (2018) *NHS Workforce Statistics September, 2018*. Accessed online on 7<sup>th</sup> April, 2019 at <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/september-2018#key-facts>

NHS England (October, 2014) *Five year forward view*. Available online, accessed on 2st June, 2019 from <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

NHS England and NHS Improvement (2020): The Framework for Enhanced Health in Care Homes Version 2, March 2020: accessed online on 15 August, 2021 at. <https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/>

NHS Information Centre, (2010). Sickiness absence rates in the NHS: October-December 2009, experimental statistics. The Health and Social Care Information Centre.

- Nelson, F.L., & Farebrow, N.L. (1980) Indirect self-destructive behaviour in the elderly nursing home patient. *Journal of Gerontology*, 35(6), 949-957. In N.S. Reiss, & C.L.Tishler, (2008b). Suicidality in nursing home residents: Part II. Special issues. *Professional Psychology: Research and Practice*, 39(3), 271-275.
- NI Direct (2019) *Paying your residential care or nursing home fees*. Accessed on 21<sup>st</sup> June, 2019 at <https://www.nidirect.gov.uk/articles/paying-your-residential-care-or-nursing-home-fees>
- Nicolson, P. (2001). Critical Health Psychology: A radical alternative to the 'mainstream'? Commentary on Crossley. *Psychology, Health and Medicine*, 6, 256-259.
- Nightingale, D.J., & J. Cromby (Eds.) (1999) *Social constructionist psychology: A critical analysis of theory and practice*. Buckingham/Philadelphia, PA: Open University Press.
- Nolan, M.R. (1997) Health and social care: what the future holds for nursing. Keynote address at Third Royal College of Nursing Older Person European Conference and Exhibition, Harrogate.
- Nolan, M. (2001) Successful ageing: Keeping the 'person' in person-centred care. *British Journal of Nursing* 10(7), 450-453.
- Nolan, M.R., Davies, S., Brown, J., Keady, J. & Nolan, J. (2002) *Longitudinal Study of the Effectiveness of Educational Preparation to Meet the Needs of Older People and Carers: The AGEIN (Advancing Gerontological Education in Nursing) Project*. English National Board for Nursing, Midwifery and Health Visiting, London (320 pp).
- Nolan, M.R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004) Beyond 'person-centred' care: a new vision for gerontology nursing. *International Journal of Older People Nursing in association with Journal of Clinical Nursing*, 13(3a), 45-53.
- Nolan, M.R., Brown, J., Davies, S., Nolan, J. & Keady, J. (2006) The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (Grip) Report No 2.

Project Report. University of Sheffield. Accessed on 25<sup>th</sup> June, 2019 at <https://core.ac.uk/download/pdf/99946.pdf>

O'Farrell, C. (2005) *Michel Foucault; Discontinuity and Discourse*. London, Sage

Office for National Statistics (2014) *Changes in the older resident care home population between 2001 and 2011*. Accessed on 24 April, 2019 at <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/changes-in-the-older-resident-care-home-population-between-2001-and-2011/rpt---changes-in-the-older-resident-care-home.html>

Office for National Statistics (2017) *National Population Projections: 2016-based statistical bulletin*. Accessed online on 17<sup>th</sup> June, 2019 at <file:///C:/Users/Dennis/Downloads/National%20Population%20Projections%202016-based%20statistical%20bulletin.pdf>

Office for National Statistics (August) (2018) *Living longer: how our population is changing and why it matters*. Accessed online on 7<sup>th</sup> April, 2019 at <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13>

O'Reilly, K. (2005). *Ethnographic methods*. Routledge.

O'Reilly, K. 2007(a) Ethical ethnography. In *Ethnographic Methods* (pp. 59-83). Routledge, Taylor & Francis Group, London and New York.

O'Reilly, K. 2007(b) Participating and observing. In *Ethnographic Methods* (pp. 84-111). Routledge, Taylor & Francis Group, London and New York.

Osgood, N.J. (1992) Environmental factors in suicide in long-term care facilities. *Suicide and Life-Threatening Behaviour*, 22, 98-106. In N.S. Reiss, & C.L. Tishler, C. L. (2008a). Suicidality in nursing home residents: Part I. prevalence, risk factors, methods, assessment, and management. *Professional Psychology: Research and Practice*, 39(3), 264-270.

- Palacios-Cen~ a, D., Cachon-Perez, J. M., Gomez-Perez, D., Gomez-Calero, C., Brea-Rivero, M., & Fernandez, D. E. L.-P. C. (2013). Is the influence of nurse care practices and nursing home organization understood? A qualitative study. *Journal of Nursing Management*, 21(8), 1044–1052.  
<https://doi.org/10.1111/j.1365-2834.2012.01445.x>
- Palacios-Cen~ a, D., Gomez-Calero, C., Cachon-Perez, J. M., Velarde-Garcia, J. F., Martinez-Piedrola, R., & Perez-De-Heredia, M. (2016). Is the experience of meaningful activities understood in nursing homes? A qualitative study. *Geriatric Nursing*, 37(2), 110–115.  
<https://doi.org/10.1016/j.gerinurse.2015.10.015>
- Parker, I. (1992) *Discourse dynamics: Critical analysis for social and individual psychology*. London: Routledge.
- Parker, I. (1999) Critical psychology: critical links. *Annual Review of Critical Psychology*, 1, 3-18.
- Parker, I. (2007) *Revolution in Psychology: Alienation to emancipation*. London Pluto. Cited In D. Howitt, (2010) *Introduction to qualitative research methods in psychology*, p228. Pearson Education Limited.
- Pecheux, M. (1982) *Language, Semantics and Ideology*, London, Macmillan. In M. Wetherell, S. Taylor, & S.J. Yates (Eds.) (2008) *Discourse as data: A guide for analysis*, p233. London, Sage.
- Percival, J. (2000) Gossip in sheltered housing: its cultural significance and social implications. *Ageing & Society*, 20, 303-325. In T. Gamiel, & H. Hazan (2006). The meaning of stigma: Identity construction in two old-age institutions. *Ageing & Society*, 26, 355-371.
- Persky, G., Nelson, J., Watson, J., & Bent, K. (2008) Creating a profile of a nurse effective in caring. *Nursing Administration Quarterly*, 32(1), 15-20.
- Personal Care at Home Act (2010). The Stationery Office, Crown Copyright. Retrieved on May 03, 2012 from  
[http://www.legislation.gov.uk/ukpga/2010/18/pdfs/ukpga\\_20100018\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/18/pdfs/ukpga_20100018_en.pdf)

- Phoenix, C., Smith, B., & Sparkes, A. (2010) Narrative analysis in aging studies: A typology for consideration. *Journal of Aging Studies*, 24:1-11.
- Picard, C. (1991) Caring and the story: The compelling nature of what must be told and understood in the human dimension of suffering. In D. Gaut & M. Leininger (Eds), *Caring: The compassionate healer* (pp 89-98). New York: National League for Nursing Press.
- Picard, N. M. (2001). The construction of self as caring: Personal care workers in home care with elderly clients. ProQuest Information & Learning). *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 61 (8-B), 4465-4465. (Electronic; Print)
- Pierson, C.A. (1999). Ethnomethodologic analysis of accounts of feeding demented residents in long-term care. *Journal of Nursing Scholarship*, 31(2), 127-131.
- Pines, A.M. (2002) A psychoanalytic-existential approach to burnout: Demonstrated in the cases of a nurse, a teacher, and a manager. *Psychotherapy: Theory/Research/Practice/Training*, 39(1), 103-113.
- Pink, S. (2007). *Doing visual ethnography: Images, media and representation in research*. Sage.
- Pleschberger, S. (2007) Dignity and the challenge of dying in nursing homes: the residents' view. *Age and Ageing*, 36, 197-202.
- Popham, C., & Orrell, M. (2012). What matters for people with dementia in care homes? *Aging and Mental Health*, 16(2), 181–188. <https://doi.org/10.1080/13607863.2011.628972>
- Porteus, J. & Spence, G. (2010) *From the ground up: A report on integrated care design and delivery*. Institute of Public Care (IPC). Retrieved on May 02, 2012 from [http://ipc.brookes.ac.uk/publications/pdf/From\\_The\\_Ground\\_Up\\_-\\_A\\_guide\\_to\\_integrated\\_care\\_and\\_delivery\\_Final\\_Nov.pdf](http://ipc.brookes.ac.uk/publications/pdf/From_The_Ground_Up_-_A_guide_to_integrated_care_and_delivery_Final_Nov.pdf)



- Potter, J., Edwards, D. & Ashmore, M. (1999). *Regulating criticism: Some comments on an argumentative complex*. *History of the Human Sciences*, 12, 79-88.
- Potter, J., & Wetherell, M. (1987) *Discourse and Social Psychology: Beyond attitudes and behaviour*. London, Sage.
- Potter, R., Sheehan, B., Cain, R., Griffin, J., & Jennings, P. A. (2018). The impact of the physical environment on depressive symptoms of older residents living in care homes: A mixed methods study. *The Gerontologist*, 58(3), 438–447. <https://doi.org/10.1093/geront/gnx041>
- Quigley, M., Jupp, R., (Editors) & Plomin, J. (Director) (22 May 2019). *Undercover Hospital Abuse Scandal [Panorama]*. In Bendelow, I., Plomin, J., & Whightman, K. (Producers). BBC, United Kingdom. Accessed online on 26 May, 2019 at <https://www.bbc.co.uk/iplayer/episode/m00059qb/panorama-undercover-hospital-abuse-scandal>
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: Sage.
- Radley, A. (2009) *Works of illness; Narrative, picturing and social response to serious disease*. InkerMen Press.
- Radley, A., Hodgetts, D. & Cullen, A. (2005). Visualising homelessness: A study in photography and estrangements. *Journal of Community and applied social Psychology*, 15, 273-295.
- Radley, A., & Taylor, D. (2003a). Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Health Research*, 13(1), 77-99.
- Radley, A. & Taylor, D. (2003b). Remembering one's stay in hospital: A study in recovery, photography and forgetting. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 7(2), 129-159.
- Rantz, M., Jensdóttir, A.B., Hjaltadóttir, I., Gudmundsdóttir, I., Sigurveig Gudjónsdóttir, J., Brunton, B., & Rook, M. (2002) International field test



results of the observable indicators of a nursing home care quality instrument. *International Nursing Review*, 49, 234-242.

Reiss, N. S., & Tishler, C. L. (2008a). Suicidality in nursing home residents: Part I. prevalence, risk factors, methods, assessment, and management. *Professional Psychology: Research and Practice*, 39(3), 264-270.

Reiss, N. S., & Tishler, C. L. (2008b). Suicidality in nursing home residents: Part II. Special issues. *Professional Psychology: Research and Practice*, 39(3), 271-275.

Richards, T., Coulter, A. & Wicks, P. (2015) Time to deliver patient-centred care. *BMJ* 350(3). Editorial 350:h530 accessed on 25 June, 2019 at <https://www.bmj.com/content/350/bmj.h530>

Ricoeur, P. (1979) The human experience of time and narrative. In M.J. Valdes (Ed.) *A Ricoeur reader: Reflection and imagination* (pp. 435-437). Tronto, University of Tronto Press.

Ricoeur, P. (1992) *Oneself as another*. Chicago: University of Chicago Press.

Rodrigues, R., & Schmidt, A.E. (2010) Expenditures for long-term care: At the crossroads between family and state. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 23(4), 183-193.

Rodríguez-Martín, B., Martínez-Andrés, M., Cervera-Monteagudo, B., Notario-Pachecho, B., & Martínez-Vizcaíno, V. (2013). Perception of quality of care among residents of public nursing-homes in Spain: A grounded theory study. *BMC Geriatrics*, 13, 65. Accessed online on 15 August, 2021 at <https://doi.org/10.1186/1471-2318-13-65>

Rosvik, J., Brooker, D., Mjorud, M., Kirkevold, O. (2013) What is person-centred care in dementia? Clinical reviews into practice: the development of the VIPS practice model. *Reviews in Clinical Gerontology*, 23, 155-163  
doi:10.1017/1059259813000014

Rothera, I.C., Jones, R., Harwood, R., Avery, A.J., & Waite, J. (2002) Survival in a cohort of social services placements in nursing and residential homes:

factor associated with life expectancy and mortality. *Public Health*, 116(3), 160-165.

Royal College of Nursing [RCN] (2010). Policy Briefing: Care homes under pressure - an England report. *Royal College of Nursing*, 1-19. Retrieved on May 03, 2012 from [http://www.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0006/314547/Policy\\_Report-Care\\_Homes\\_under\\_pressure\\_final\\_web.pdf](http://www.rcn.org.uk/__data/assets/pdf_file/0006/314547/Policy_Report-Care_Homes_under_pressure_final_web.pdf)

Royal College of Nursing [RCN] (2019) *Nursing in Care Homes: A view from the frontline*. Retrieved on 24 April, 2021 from <https://www.rcn.org.uk/news-and-events/news/cross-party-group-examines-nursing-in-care-homes>

Royal College of Psychiatrists (2013) National Audit of Dementia care in general hospitals 2012-2013: Second round audit report and update. Editors: Young, J., Hood, C., Gandesha, A. and Sousa, R. London: HQIP. Accessed online on 04.03.2014 at <http://www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013.pdf>

Ruthrof, H. (1997) *Semantics and the body*. Toronto, ON: University of Toronto Press.

Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008) Using the senses framework to achieve relationship-centred dementia care services. *Dementia*, 7(71). DOI: 10.1177/1471301207085368

Sanakova, S., & Cap, J. (2019) Dignity from the nurses' and older patients' perspective: A qualitative literature review. *Nursing Ethics*, 26(5), 1292-1309 doi:10.1177/0969733017747960

Schlesinger, M., & Dorwart, R. (1984) Ownership and mental-health services. A reappraisal of the shift toward privately owned facilities. *New England Journal of Medicine*, 311, 959-965. In W.R. Shadish (1989) Private-sector care for chronically mentally ill individuals: The more things change the more they stay the same. *American Psychologist*, 44(8), 1142-47.

- Searle, J.R. (1995) *The construction of social reality*. New York, Free Press.  
DOI 10.1086/233794
- Shadish, W.R., (1989) Private-sector care for chronically mentally ill individuals: The more things change the more they stay the same. *American Psychologist*, 44(8), 1142-47.
- Sheffield Local Involvement Network (LINK) (2011) *Care homes for older people: Interim report on the care homes for older people action group*. Sheffield Local Involvement Network (LINK), 1-38.
- Sherlaw-Johnson, C., Smith, P, & Bardsley, M. (2015) Continuous monitoring of emergency admissions of older care home residents to hospital. *Age and Ageing* 45(1): 71-77: doi.org/10.1093/agig/afv158 Accessed on 17<sup>th</sup> June, 2019 at <https://academic.oup.com/ageing/article/45/1/71/2195296>
- Shultz, R., & Brenner, G. (1977) Relocation of the aged: A review and theoretical analysis. *Journal of Gerontology*, 32, 323-333. Accessed on 25<sup>th</sup> February, 2014 at <https://academic.oup.com/geronj/article-abstract/32/3/323/565413>
- Silverman, D. (2004) Ed. *Qualitative research: Theory, method and practice*. London, Sage.
- Silverman, D. (2005) *Doing qualitative research*. London, Sage.
- Simmons, S.F., Cadogan, M.P., Caberara, G.R., Al-Samarria, N.R., Jorge, J.S., Levy-Storms, L., et al (2004) The Minimum Data Set depression quality indicator: does it reflect differences in care processes? *The Gerontologist*, 44, 554-564. In N.S. Reiss, & C.L. Tishler, (2008a). Suicidality in nursing home residents: Part I. prevalence, risk factors, methods, assessment, and management. *Professional Psychology: Research and Practice*, 39(3), 264-270.
- Sims-Schouten, W., Riley, S.C.E., Willig, C. (2007) Critical Realism in Discourse Analysis: A presentation of systematic method of analysis using women's talk of motherhood, childcare and female employment as an example. *Theory Psychology*, 17, 101-124.

- Somers, M.R. (1994) The Narrative Constitution of Identity: A Relational and Network Approach. *Theory and Society* 23(5), 605-649 Accessed on 24 March 2019 at [https://www.jstor.org/stable/658090?seq=1#page\\_scan\\_tab\\_contents](https://www.jstor.org/stable/658090?seq=1#page_scan_tab_contents)
- Stanczak, G.C. (2009) *Visual Research Methods: Image, Society and Representation*. SAGE Publications (CA).
- Steinar, K., (1996) An introduction to qualitative research interviewing. Sage Publications Ltd. ISBN 080395820X, 9780803958203
- Stephens, C. (2011) Narrative analysis in health psychology research: Personal, dialogical and social stories of health. *Health Psychology Review*, 5(1), 62-78.
- Stephens, C. & Breheny, M. (2013) Narrative analysis in psychological research: An integrated approach to interpreting stories. *Qualitative Research in Psychology*, 10(1), 14-27.
- Sterns, S., & Kahana, E. (2007) Institutional constraints on residents in long-term care facilities for the elderly. *Research in the Sociology of Health Care*, 24, 1-20.
- Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: A review. *Canadian Medical Association Journal*, 152(9), 1423–1433.
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In Austin, W.G., Worchel, S. (eds.) *The social psychology of intergroup relations*. Monterey, California: Brooks/Cole, pp. 33-47
- Teresi, J., Abrams, R., Holmes, D., Ramirez, M., & Eimicke, J. (2001) Prevalence of depression and depression recognition in nursing homes. *Social Psychiatry and Psychiatric Epidemiology*, 36(12), 613-620. In N.S. Reiss, & C.L. Tishler, (2008b). Suicidality in nursing home residents: Part II. Special issues. *Professional Psychology: Research and Practice*, 39(3), 271-275.

Terry, R., & Gibson, R. (2010) *Can equity release help older home-owners improve their quality of life?* Joseph Rowntree Foundation, ref:2429.

The Cavendish Review (2013) *An independent review into healthcare assistants and support workers in the NHS and social care settings.*

Accessed online on 10.03.2014 at

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/236212/Cavendish\\_Review.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/236212/Cavendish_Review.pdf)

The Kings Fund (Online) (2020) Social Care 360: expenditure. Accessed on 24 April, 2021 at <https://www.kingsfund.org.uk/publications/social-care-360/expenditure>

Treweek, G.L. (1996) Emotion work, order, and emotional power in car assistant work. In V. James & J Gabe (Eds), *Health and the sociology of emotions*. Oxford, Blackwell. In C. Berdes and J. Eckert, (2007) The language of caring: Nurse's aides' use of family metaphors conveys affective care. *The Gerontologist*, 47(3), 340-340-9.

Treweek, G. (2000). The insight of emotional danger: research experiences in a home for older people. In G. Lee-Treweek & S. Linkogle (Eds.) *Danger in the field: Risk and ethics in social research*. Routledge, London.

Tronto, J.C. (1993) *Moral Boundaries: A political argument for an ethic of care*. New York, Routledge.

Tronto, J.C. (1998) An Ethic of Care. *Generations*, 22(3), 15-20.

Tuckett, A. G. (2005). Residents' rights and nurses' ethics in the Australian nursing home. *International Nursing Review*, 52(3), 219-224.

Tuckett, A.G. (2006) On paternalism, autonomy and best interests: Telling the (competent) aged-care resident what they want to know. *International Journal of Nursing Practice*, 12, 166-173.

Tuckett, A.G., Hughes, K., Schluter, P.J., & Turner, C. (2009) Validation of CARE-Q in residential aged care: rating of importance of caring behaviours from an e-cohort study. *Journal of Clinical Nursing*; 18(10): 1501-1509.

- Umoquit, M. Dobrow, M., Iemieux-Charles, L., Ritvo, P., Urbach, D., & Wodchis, W. (2008). The efficiency and effectiveness of utilising diagrams in interviews: An assessment of participatory diagramming and graphic elicitation. *BMC Medical Research Methodology*, 8, 53. Retrieved on May 18, 2012 from <http://www.biomedcentral.com/1471-2288/8/53>.
- van Hoof, J., Verbeek, H., Janssen, B. M., Eijkelenboom, A., Molony, S. L., Felix, E., Nieboer, K. A., Zwerts-Verhelst, E. L., Sijstermans, J. J., & Wouters, E. J. (2016). A three perspective study of the sense of home of nursing home residents: The views of residents, care professionals and relatives. *BMC Geriatrics*, 16(1), 169. <https://doi.org/10.1186/s12877-016-0344-9>
- Vizedom, M.B. (1976) *Rites and Relationships: Rites of Passage and Contemporary Anthropology*. Beverly Hills, CA, Sage.
- Walker, H., & Paliadelis, P. (2016). Older peoples' experiences of living in a residential aged care facility in Australia. *Australasian Journal on Ageing*, 35(3), E6–E10. <https://doi.org/10.1111/ajag.12325>
- Walsh, K., & Kowanko, I., (2002) Nurses' and patients' perceptions of dignity. *International Journal of Nursing Practice*, 8, 143-151.
- Wang, C., & Burris, M. (1997) Photovoice: concept, methodology, and use for participatory needs assessment. *Health Education and Behaviour*, 24, 369-387.
- Wang, J, Wang, J, Cao, Y, Jia, S, & Wu, B. (2016). Older residents' perspectives of long-term care facilities in China. *Journal of Gerontological Nursing*, 42(8), 34–43. Accessed online on 15 August, 2021 at <https://doi.org/10.3928/00989134-20160615-05>
- Wetherell, M., Taylor, S., & Yates, S.J. (2001) *Discourse theory and practice*. Sage Publications Ltd.
- Wetherell, M., Taylor, S., & Yates, S.J. (2008) *Discourse as data: A guide for analysis*. London, Sage.

- Wild, D., Szczepura, A., & Nelson, S. (2010) Residential care home support workforce development: The rhetoric and reality of meeting older residents' future care needs. Joseph Rowntree Foundation. Retrieved on May 04, 2012 from [www.jrf.org.uk](http://www.jrf.org.uk)
- Williams, D.H., Bellis, E.C., & Wellington, S.W., (1980) Deinstitutionalisation and social policy: Historical perspectives and present dilemmas. *American Journal of Orthopsychiatry*, 50, 54-64. In W.R. Shadish, (1989) Private-sector care for chronically mentally ill individuals: The more things change the more they stay the same. *American Psychologist*, 44(8), 1142-47.
- Williams, S.J. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22(1), 40-67.
- Wills, T.A. (1981) Downward comparison principles in social psychology. *Psychological Bulletin*, 90(2), 245-271
- Wilson, K.G., Curran, D., & McPherson, C.J. (2005) A burden to others: A common source of stress in the terminally ill. *Cognitive Behaviour Therapy*, 34(2):155-123. <http://dx.doi.org/10.1080/16506070510008461>
- Wittenberg, R., Comas-Herrera, A., Pickard, L., & Hancock, R. (2004) Future Demand for Long-term Care in the UK: A Summary of Projections of Long-term Care Finance for Older People to 2051. York: Joseph Rowntree Foundation. In D. Hirsch, (2005) Facing the cost of long-term care: Towards a sustainable funding system. Joseph Rowntree Foundation, 1-46. Retrieved on May 02, 2012 from <http://www.jrf.org.uk/sites/files/jrf/1859353894.pdf>
- Wood, R., & Bain, M.R.S. (2001) *The Health and Well-being of Older People in Scotland: Insights from National Data*. Edinburgh: Information and Statistics Division.
- Woolhead, G., Calnan, M., Dieppe, P., Tadd, W. (2004) Dignity in older age: What do old people in the United Kingdom think? *Age and Ageing*, 33, 165-170.

Zhang, B., Mitchell, S. L., Bambauer, K. Z., Jones, R., & Prigerson, H. G.  
 (2008). Depressive symptoms trajectories and associated risks among  
 bereaved Alzheimer's disease caregivers. *American Journal of Geriatric  
 Psychiatry*, 16, 145–155.

## Acronyms

Acronym	Full Name
BBC	British Broadcasting Company
DoH	Department of Health
LiNk	Local Involvement Network
NHS	National Health Service
PhD	Doctorate in Philosophy
UK	United Kingdom



## Appendices

Appendix Number	Appendix Name
0.1 – 0.6	Overall Thesis Related Appendices
0.1	Sheffield Hallam University (SHU) Ethics Proforma
0.2	SHU ethics committee approval letter
0.3	Local Authority ethics committee approval
0.4	DBS clearance
0.5	Ethical Issues in Observations and Visual Methods
0.6	Statement of Postgraduate Study
1.1 – 1.10	Chapter 3 – Study 2: Observations in Nursing Homes
1.1	Obs Info for Participants
1.2	Obs Consent form
1.3	Obs consent for photographs
1.4	Obs debrief
1.5	Ethical issues associated with ethnographic observations using photos
1.6	Bracketing methods and reflexivity
1.7	Field notes extract nursing home 1 annotated
1.8	Foucault's theory of knowledge as power and methodology 'genealogy and archaeology'.
1.9	FDA: 6 steps to analysis & findings
1.10	Example photographs in each participating nursing home
2.1 – 2.11	Chapter 4 – Study 3: Focus Group (FG) with nursing home staff
2.1	Staff FG advertising poster
2.2	Staff FG Information Sheet
2.3	Staff FG Volunteer Slip

2.4	Staff FG Consent Form
2.5	Staff FG Demographic Information
2.6	Staff FG Topic Guide
2.7	Staff FG Object Elicitation: Begonia
2.8	Staff FG Maddie's poem and nurse's reply
2.9	Staff FG Debrief Sheet
2.10	Staff FG Orthographic Transcription Annotation
2.11	Staff FG Coding data
3.1 – 3.10	Chapter 5 – Study 4: Interviews with nursing home residents
3.1	Res Int Information Sheet
3.2	Res Int Volunteer Slip
3.3	Res Int Contact preference
3.4	Res Int Consent Form
3.5	Res Int Consent Photos (in full)
3.6	Res Int Consent Photos (anonymised)
3.7	Res Int Debrief Sheet
3.8	Res Int Annotated transcription using NA
3.9	Res Int Coding data into themes
3.10	Res Int Reflections on photo-elicitation and NA