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DOMICILIARY CARE, SELF
AND OLDER AGE

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ABSTRACT

Social care funding is reducing in spite of a growing older population. Within this context, domiciliary services are increasingly failing to deliver care that respects the individuality and heterogeneity of older people (Equality and Human Rights Commission, 2011). To date, there has been limited research in the U.K. that explores, from the older person's perspective, how care practices interact with self.

Using biographical narrative methodology, this study takes a constructionist approach to understand the individual's lived experience of care and how it interacts with sense of self. A three stage model of data collection was used, beginning with a narrative biographic enquiry, exploring with participants (65yrs+, n=17) their journeys into care and any consequential effects on personal identity. Stage 2 involved a two week period of diary completion, with participants recording daily reflections on their care experiences. In stage 3, a semi-structured interview explored the diary entries, linking back to the narrative biographic enquiry to reveal ways in which specific care practices interacted with the sense of self.

The findings reveal that a strong relationship between older person and carer, forged through familiarity, regularity and consistency, plays a significant role in promoting feelings of autonomy and dignity. Furthermore such relationship mediates against the loss of executional autonomy that comes with increasing disability. Maintaining autonomy and control was a recurring theme, including in relation to one's home, one's privacy and one's dignity. Findings also reveal increased feelings of autonomy and dignity when carers understand the unique ways in which individuals experience ageing and being in the cared-for relationship.

These findings make an important contribution to the body of work concerning best practice in delivery of domiciliary care that respects older people's sense of self. Furthermore, the narrative approach used within this study, and in particular the three stage data collection method of the narrative biographic enquiry, the diary and the follow-up interview, provides a valuable contribution to methodological knowledge.

Keywords: 'domiciliary care', ageing, self, identity

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I would like to thank those individuals and organisations that generously assisted with recruitment. Finally, and most importantly, I would like to recognise the contribution of those older people who took part in this research. Thank you for sharing your stories. It has been a real privilege.

DECLARATION

I confirm that this thesis, presented for the degree of Doctor of Philosophy, has been composed entirely by myself, has been solely the result of my own work and has not been submitted for any other degree or professional qualification.

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Chapter 1

Introduction

“Ethel... makes me feel special, that I am the only person she sees and we have a good laugh. She just talks to you like you’re a person ...and treats me like an individual” (quote from Susan).

This research is borne out of my need to understand, from the older person’s perspective, what it is like to receive care in their own home. I want to hear from older people how they feel when a carer comes into their very personal home space but also, as is often the case, into their own body space. I explore how self is preserved during the caring process and the importance placed on this for older people. Equally, I am interested in the extent to which they feel the need to maintain a degree of autonomy and whether this is possible within the care arrangements they received. The primary intention of this research is to gain knowledge and insight of the older person’s perspective on their sense of self and whether it is maintained within the care dynamic. In the process of exploring how care interacts with sense of self, the study does shine a light on elements of the quality of domiciliary care practices. However, the way in which these services are managed and delivered is not the focus of this research, nor is measuring or assessing the quality of services.

My interest in this area of care began whilst working as a domiciliary carer. I worked for a year with several older people, attending to their often very personal needs. I then qualified as a social worker and I increasingly reflected on how the way in which care is delivered affects the older person’s sense of self. I saw how much the lateness of calls affected autonomy and dignity, how being a regular carer helped a relationship to grow and the value of this relationship, and how socially isolated some of the older people were and the value they placed on our interaction. Yet I also observed how different their needs were. For some the importance of the relationship that developed was hugely significant, whilst for others it was the quality and timeliness of the completion of care tasks that was paramount. I observed how for some the need to maintain control over their lives was crucial, and also how that loss of personal dignity affected them quite dramatically. The uniqueness of individuals within this setting became apparent, and I began to wonder to what extent care organisations and carers consider the heterogeneity of older people and what kinds of care practices promote this

individuality. Furthermore, I wanted to understand how care practices are received by older people.

I searched literature for a better understanding of these issues, and the way in which older people are cared for in their homes has been the subject of many enquiries over recent years. However, my search of literature revealed that many of these studies have focused on the way in which domiciliary care is delivered, looking for the improvement of services through new methods, and focusing on the way in which domiciliary care services are managed. Gethin-Jones (2012b) looks at the benefits of implementing outcome-focused care rather than task-centred care whilst Glendinning et al. (2008) draw attention to the challenges faced by Local Authorities in the implementation of the outcome-focused model. Other studies have worked directly with older people to explore how they view the quality of social care services (Francis and Netten, 2004, Qureshi and Henwood, 2000). I found very little literature that focuses on how older people are affected, both physically and emotionally, by the way in which domiciliary care services are delivered. Patmore's study with older people (2004) does look at not only whether care meets the physical needs, but also at how domiciliary care practices affect morale and psychological well-being. However, since his study in 2004, the reduction in social care budgets has impacted heavily on the way in which home care is delivered. Financial austerity over the last decade has resulted in the reducing of social care budgets, with Local Authority departments forced to make savings of 12 per cent, the equivalent of £3.53 billion over the last four years (ADASS, 2012). Yet the older population is growing, with the proportion of people aged over 65 expected to rise across the UK from 18% in 2016 to 24.7% by 2036 (ONS, 2017). Furthermore, the number of those aged 85 is projected to increase by 113.9 per cent, from nearly 1.3 million people to just under 2.8 million in 2035/36 (ONS, 2017). The Local Government Association's Well-being Board (2012) expressed serious concerns that a growing funding crisis will jeopardise Local Authority services. The Equality and Human Rights Commission (2011) carried out a survey of Local Authorities, care providers and service-users across England and uncovered "serious systemic threats to the basic human rights of older people who are getting home care services" (p.7) and figures from the industry regulator, the Care Quality Commission (2015) show that more than a quarter of home care companies are not meeting standards. Yet whilst the home care sector is in crisis, my search of literature found few studies that focus specifically on how care in the home interacts with an older person's sense of self, promoting feelings of autonomy, and dignity. Whilst reports may highlight where services fail and

where they succeed, the psychological impact of domiciliary care on the older person has been somewhat neglected.

Hence my research questions developed:

1. How are domiciliary care practices experienced by older people?
2. To what extent is domiciliary care delivered in a way that considers sense of self?
3. How do care practices link to autonomy and how important is this for sense of self?

It is these questions, along with my own ontological and epistemological position that have guided my research design. To fully grasp how the older person's self may be affected by the way in which care is delivered, I explore the circumstances surrounding their personal and individual journey, and how they feel their changed circumstances impact on their sense of self and the biographical-narrative approach is at the heart of my research. Storytelling is the universal way in which people communicate and reinterpret and make sense of their life experiences. It can be used as a way to gain insight into the complex relationship between these experiences, the meanings that people apply to them, how they respond, and the social and societal contexts in which they occur (Andrews et al., 2008). However, to fully understand the ways in which the older person is affected by care practices, I follow the biographical-narrative with a diarised daily account of care activities. Finally, during the follow-up interview I explore these care activities against the backdrop of the narrative to try to discover how the older person feels about the incidents they record and particularly how they affect their sense of self.

The structure of the thesis

In the following chapter I explore how domiciliary care has evolved, how older people negotiate the care system and attempt to secure the best fit service, and how some needs remain unfulfilled. I also discuss the personalisation agenda and how different models of care delivery, including outcomes-focused care, task-centred care and personal budgets have been received by older people.

The third chapter, the literature review, explores the concepts of self and identity including a psychological and sociological discussion around social constructionism, symbolic interactionism, role theory and life stage theory. This literature review looks at studies

exploring how older people in receipt of care feel about getting older and receiving care, including such concepts as subjective ageing, agelessness, and the 'mask of ageing'. The review then goes on to discuss external forces that influence how older people experience ageing including social constructionism, political economy, personal agency and ageism. I discuss how the societal attitudes to ageing interact at the individual level and the potential they have to impact on an older person's sense of self. In the final section of the literature review I look to current domiciliary care practices to explore the extent to which services reach beyond satisfying the purely physical aspect of the care plan in order to fulfil the psychosocial needs of older people. I thread into this the previously discussed concepts of care, ageing and self and how care affects older people's feelings of autonomy, dignity and self-esteem.

Chapter 4, Methodology, very much follows a traditional structure including discussion around my methodology, the research design and the data collection methods I employ. I begin by stating my ontological and epistemological position and how this guided me towards the biographical narrative methodology, and how it influenced the choice of data collection methods including the biographical-narrative, diary and the follow up-interview. Following on is an exploration of the ethical issues around the data collection stage, including confidentiality, how I managed the recruitment of participants and a summary of the final sample. I then go on to explain how I carried out my data analysis, the issues around my involvement as a researcher and finally the trustworthiness of the data including validity and reliability.

Through the analysis of the data across the narratives, diaries and interviews I generated four themes: self, identity and getting older, autonomy, voicing concerns and social contact. In Chapter 5 I present findings across these themes.

I then go on, in the interpretive Chapter 6, to my discussion, setting it in the context of the literature review. One of the most significant themes that emerges is the importance of valuing the older person as an individual and appreciating and understanding the unique ways in which people age and adapt to being cared for at home. At the same time the value of the relationship between carer and cared-for is an important theme across the findings with relational care, realised through regular and consistent care being dominant. Threading through much of the findings is also the importance of both executional and decisional

autonomy, with the timings of calls, the focus on tasks or outcomes, and the value of the home space being influencing factors.

In the concluding chapter 7, I reflect on and critique the research, highlighting where it provides contribution to knowledge. I discuss its strengths and limitations, and make recommendations for further research. I also consider where the research can support health and social care.

I include in the appendices all of the documentation that I accrue through the research journey, including the ethical approval, examples of the biographical narrative, the interview and the diary formats, and the participant information sheets and consent forms.

Chapter 2

The evolution of domiciliary care and the current context

The concept of care is multifaceted. It crosses the boundaries of political, economic, philosophical and ideological debates, addressing a plethora of issues such as who funds care, who delivers care, who receives care, and how, when and where it is delivered. Care takes place, at some level, from cradle to grave, thus calling upon different policy contexts. Yet care also takes place across generations, against a backdrop of changing political and social contexts. The service landscape changes over time, and who delivers care, who is ultimately responsible for care and who pays for care is determined by the political, societal, individual and economic contexts at any given time and the relationship between carer and cared-for is affected by policy development, often in response to economic demand.

Across this complex network of care contexts are a range of definitions, understandings and forms of knowledge about care, and each of these are subject to change across the time continuum. In this sense then care is a socially constructed phenomenon and in order to understand what it means to individuals I will examine the literature using a constructionist approach

In this chapter I explore literature in an attempt to understand and interpret where and why there may be sites of tension between care commissioner, care giver and care receiver within the domiciliary care context. I begin by mapping the various sources of care that are available to an older person before focusing on domiciliary care and charting the evolution of home care services. I then look to the personalisation agenda and how it has influenced both the way in which care is funded and the way in which care is developed through different models of care. I then go on to discuss current home care policy looking at eligibility criteria, needs assessment and the aims of the 2015 Care Act.

Exploring the context of domiciliary care in this way sets the backdrop for this research, since it is within this environment of care that I seek to understand how older people's selves are respected and sustained.

2.1 Different sources of care

When an older person needs care, that care can come from either the NHS, Local Authority Social Services or the voluntary sector (see figure 1). Whilst healthcare provided by the NHS, is free, social care is provided by Local Authority Social Services, and can be chargeable depending on a financial assessment. Healthcare includes treating or controlling illness, disability or injury, whilst social care and personal care includes helping someone to get washed, dressed and toileted, providing help at mealtimes, or supporting someone to get out and about.

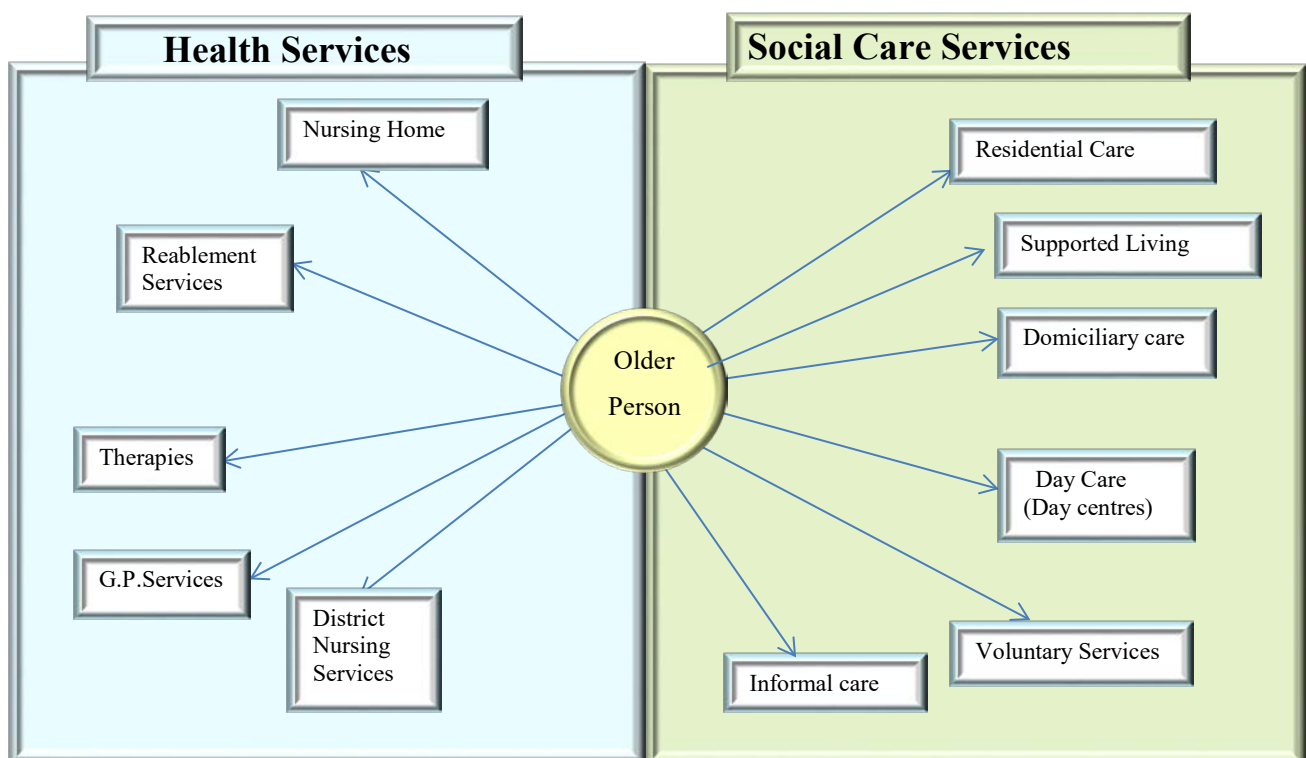


Figure 1: Care services for older people aged 65+

Care can be provided within a nursing home, a residential setting, or the home:

- An older person will go into a **nursing home** if they need medical care and they have a primary health need such that the majority of the care they require is focused on addressing or preventing health needs. Medical care in a nursing home is funded by the NHS.
- An older person may go into a **residential home** if there is deterioration in their physical health or mobility or in their mental health which limits their ability to stay

safely in their own home, if they lack needed support of a partner, family or friends with their care at home or they suffer from loneliness, isolation or depression. Residential care, being social care and not health care, is funded either privately or by the Local Authority.

- **Sheltered housing** is provided either as rented or privately purchased accommodation, typically set in schemes of between 20 and 40 self-contained apartments or bungalows on one site, allowing older people to live independently, having the freedom to come and go as they please, yet being supported by, at the minimum, a scheme manager or warden, who is on hand to who give advice to residents, and a 24-hour alarm system in case of emergency.
- An older person will receive **domiciliary care** in their own home, including in sheltered accommodation, when they are finding it difficult to cope with daily routines, such as washing, dressing or getting out and about when their property still meets their needs and is suitable and safe for them to live in and when they choose not to go into residential care home. Domiciliary care services provide care workers who give help and support with acts of daily living, including getting out of bed in the morning, washing, dressing, toileting, using continence aids, preparing meals and drinks, eating and drinking and giving, or prompting to take, prescribed medication. Home care is either wholly or partially funded by the Local Authority or is self-funded depending on a financial assessment. Home care can also be delivered by way of informal care, that is by friends and family, who provide either paid or unpaid care outside a professional or formal employment framework and the role of the informal carer in supporting the older person at home is steadily growing (Milligan, 2009). The voluntary sector provides support, and day care, in the form of day centres, also plays a major role in contributing to the care of older people in the community.

The ratio of older people using domiciliary care services as opposed to residential or nursing care has changed dramatically over the last three decades and in the following section I explain its growth. However, throughout this research I allude to the paucity of research into older people's domiciliary care services, and in particular how such services interact with sense of self, yet looking at figure 2 it is clear that domiciliary care plays a hugely significant role across the care sector.

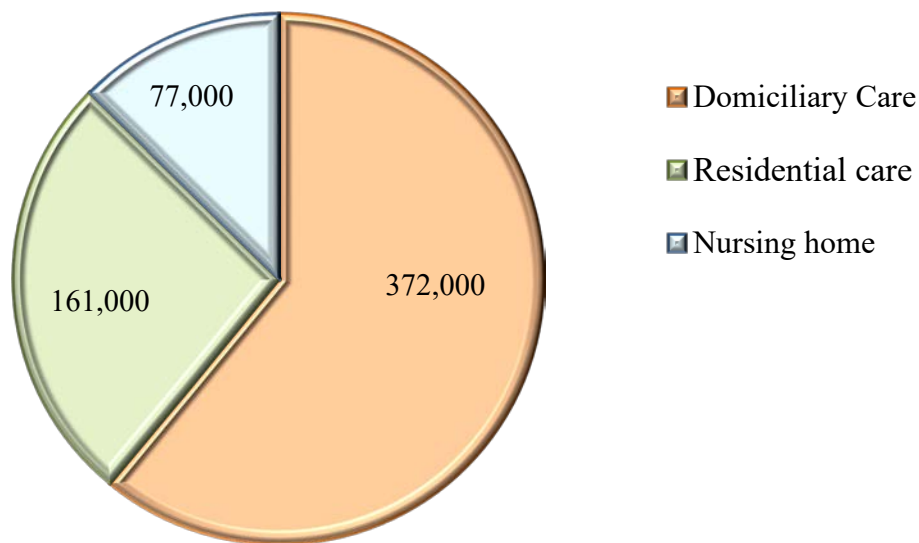


Figure 2: Number of older people aged 65+ accessing Local Authority funded or Local Authority commissioned domiciliary care, residential care or nursing home care in England during period 2013-2014 (adapted from Health and Social Care Information Centre, 2014)

I will now discuss how and why domiciliary care has become such a dominant force within the care arena

2.2 From home help to home care - the drive towards care in the community

The forerunner to the domiciliary care service, that is the domestic help and later the home help service, originated in 1894 in London's East End by way of the Sick Room Help Society to provide "household duties where the mother is confined or sick" (Abraham-Van der Mark, 1996, p.164). Tasks included normal household duties that would have been the responsibilities of the indisposed mother such as cleaning, cooking, washing and child care. Representing the voluntary and charitable sector, this group of workers were generally untrained and acted as assistants to health care professionals such as doctors, nurses and health visitors. With the introduction of the Maternity and Child Welfare Act in 1918, the service became more widespread and eventually the more reformist councils rolled it out to support not just mothers but also disabled and older people.

By 1946 the National Health Service Act introduced measures to support people through Community Health Services including domestic helps, which were to be provided by Local

Authorities and funded by Central Government and the local council rates system. However, the more frail older people were still cared for in residential settings and the domestic help was seen very much as the second best option. In 1948 though, the Maternal Assistance Act gave Local Authorities the authority to financially recompense voluntary and charitable organisations to provide meals to older people with disabilities, and to contribute towards the older person's costs in securing domestic support from the same third sector.

With the growth in the older population the demand on the Health Service grew exponentially, and the Government of the early 1960's appealed to Local Authorities to regulate and manage the home care system to ensure older people remained in their homes for as long as possible. The Local Authority Social Services Act, enforced in 1971 on the recommendation of the Seebohm Committee, rebranded domestic help to home help. It became mandatory for Local Authorities to promote the welfare of older people and to employ the voluntary sector to go out into the community, helping in the home. Whilst responsibility for the home help service was transferred from the Health Authorities to Local Authorities, the cost of residential care remained within the centralised social security budget. A person who qualified for supplementary benefit, or income support as it is now known, could enter a private or voluntary sector residential care home with the social security system paying their care fees (Jones, 2007). Local Authorities had a way to ring-fence their increasingly squeezed budgets by diverting demand to another source of funding. Consequently, through the 1980's, state funding of independent homes soared, with social security expenditure on residential and nursing homes rocketing in the period 1979 to the early nineties from £10 million to almost £2.6 billion (LaingBuisson, 1995)

In 1983, Sir Roy Griffiths reacted to these 'perverse incentives', claiming that this system failed to take into account whether residential care was the best option or whether there were alternative and more suitable arrangements. He saw the solution in passing responsibility to the Local Authority for deciding whether someone would be better cared for at home and how much this would cost. The Griffiths' Report stated that:

“To use an increasingly expensive social security provision as a safety valve to keep the lid on the pot of community provision would be inconsistent with governmental and managerial responsibility.” (Griffiths Report, 1988, para. 16).

The report and the subsequent white paper 'Caring for People', enacted in 1993 by the 1990 NHS and Community Care Act, had a dramatic effect on how home care was to be delivered and set out to promote the development of domiciliary, day and respite services that would allow people to live in their own homes wherever this was feasible. The Act very much reflected the Conservative Government's drive towards the privatisation of services using principles based on managerialism and marketization, such as compulsory competitive tendering, purchaser/provider split, contracts, incentives, competition, clinical auditing and budgetary transparency. A mixed economy of adult social care was introduced, with Local Authorities becoming service commissioners rather than service providers, passing care out to private companies and the third sector; the Government was to be 'steering not rowing' (Osborne and Gaebler, 1992). The aim was to provide services that were as efficient, effective and economical as possible, and to increase the choice and quality of services (Wistow et al., 1996). In 1992, only 2% of home care services were supplied by the private sector, but by 2005 this had rocketed to 73% (Forder, 2007), and in 2010 stood at 87% (Institute of Public Care, 2012). Furthermore, the move away from funded residential care was achieved, with the numbers of funded residential beds falling from 125,600 in 1990 to 79,700 by 1995 (LaingBuisson, 2002) and the number of Local Authority funded home care hours increasing by 57% from 1.69 million in 1992 to 2.64 million in 1997 (Government Statistical Service, 1998: Table A1). A key intention of the 1990 NHS and Community Care Act was to not only provide greater opportunity for people to remain in their homes, but would also enable the customer to be the driver of effective services. Yet it developed into a quasi-market system in which political and economic forces, rather than the needs of service users, would determine which services are commissioned (Hardy and Wistow, 1998)

2.3 From Fordism to personalisation - task-centred and outcome-focused models of care

Very much supporting the commodification of care in the 1990's, was the traditional time-task centred model of care delivery, where care needs are assessed, standardised tasks are identified and time is allocated to meet those tasks (Burns et al., 2016). To ensure care was an easily marketable commodity, it was defined into neatly packaged precise time slots in which clearly defined tasks focused on purely physical activities of daily living (Ugwumadu, 2011). This Fordist production-line model of care delivery (Parton, 1996) would allow the Local Authorities to manage their budgets more effectively by assigning costs to precisely timed services. This approach to care delivery had little space for meeting the psycho-social needs

of older people, needs that were not only difficult to define but costly and complicated to meet (Aronson, 2002). The assumption was that these needs would be met by family and friends, or, as a backstop, a charitable and supportive neighbourhood (Beresford, 2008). The Griffiths report stressed that Care in the Community should be exactly that, it should be ‘in’ the community and not ‘for’ the community. The community should be very much a source of care rather than a setting for care, thus promoting the involvement of family, friends and local communities in the support of older people in their homes. The increased reliance on informal care was no surprise to political economy theorists, including Estes (1979), Phillipson (1982), Myles (1989) and Walker (1982) who saw it as a move to manage the budget rather than for the improvement of community care services and, as Walker points out,

“It is no coincidence that policy makers' recent discovery of the family coincides with a period when the government is seeking to reduce the size of the public sector” (1982, p.32).

However in 1997, New Labour, believing that the decision-making processes at the commissioning level were disconnected from the needs of the service users (Whitfield, 2006) embarked on a journey of personalisation, focusing on the importance of consumer choice and control and clear measurable outcomes against which service providers would be measured. Outcomes-focused, user-led care was to become the alternative model of care delivery to that of the service-driven time-task model so that care would meet

“the aspirations, goals and priorities identified by service users in contrast to services whose content and/or forms of delivery are standardised or a solely determined by those who deliver them. Outcomes are by definition individualised, as they depend on priorities and aspirations of individual people.” (Glendinning, et al., 2006, p.1).

Drawing on the work by Qureshi and Henwood (2000), Glendinning et al., (2006) go on to define outcomes that are most valued by older people as falling into three clusters of social care maintenance and prevention, service processes, and change.

Maintenance and prevention outcomes, also referred to as quality of life outcomes, aim to ensure an older person leads a safe, stimulating and satisfactory life in which they have choice and control over activities and routines that meet their social, physical and emotional needs (Bamford and Bruce, 2001). This could include not only having their basic physical needs being met but also having a clean and tidy home environment, keeping alert and active,

feeling safe and secure, and having social contact and company. Qureshi and Henwood (2000) suggest that with regard to maintenance and prevention outcomes, older people place value on care and support that promotes feelings of health, wellbeing and improves quality of life. This means that care should ensure the older person feels clean and presentable in appearance, has appropriate food and drink at appropriate times and is physically comfortable. They also report that older people place value on their homes being clean and presentable for any guests which in turn can sustain social inclusion. The Shaping Our Lives research (2003) which explores valued outcomes with service users, reports how significant the presentation of home is for quality of life and how service-users valued more flexible care to include help with window and curtain cleaning. Qureshi and Henwood (2000) claim that older people also value activities that promote feelings of competence, identity and independence, including pursuing hobbies and interests. Gethin-Jones (2012a) reports, in his study of outcome-based domiciliary care, an older man valuing being able to bank up his hours of care so that the carer could accompany him to the pub to watch the football. He also evidences how some older people receiving outcomes-based care value being taken on trips including to the park, to the shops, and to visit friends and family. One of Gethin-Jones' participants valued the carer taking time to tend to her late husband's grave.

Process outcomes, on the other hand, are concerned with older people's experiences of services, such as whether they feel valued and involved, the extent to which they have a say in services and feel they are being listened to, and whether they feel valued and respected and treated as an individual (Glendinning, 2006). Qureshi and Henwood (2000) suggest that outcomes around service processes relate to older people's experiences of finding, securing and experiencing care. They suggest that older people place value on having easier access to information about care and subsequently easier and quicker access to individualised, personalised services that are efficient, respectful and promote positive relationships with care staff.

Change outcomes are concerned with making improvements in physical, mental or emotional functioning that have a positive impact on confidence and morale, life skills, social interaction and relationships and health and mobility, for example becoming more able to get around freely within the home or outside through the provision of equipment, adaptations or therapy (Social Policy Research Unit, 2000). Qureshi and Henwood (2000) report that with

regard to change outcomes, older people value support with improvements in levels of distress and anxiety, together with help with mobility including provision of assistive devices.

With outcomes at the centre of political debate, the Department of Health published the White Paper 'Our Health, our Care our Say: A New Direction for Community Services' in 2006, which was followed in 2011 by the 'New Approach to Quality and Outcomes in Social Care'. The core message of this document was to enhance well-being and the quality of life, delay and reduce the need for support, ensure the experience of care and support is a positive one and to safeguard and protect vulnerable adults. However, the implementation of outcomes-focused care has been fraught with difficulties and many care providers still employ the time-task model (Gethin-Jones, 2012b, Oxford Brookes University, 2012). Research suggests that commissioning and contracting arrangements, by their very nature, impede outcomes-focused services and in a survey conducted by the Local Government Information Unit, more than a third of Local Authorities said that it was only used 'to a limited degree' in their authority (Lucas and Carr-West, 2012). Glendinning et al. (2006) suggest that the successful and widespread implementation of outcomes-focused care is hindered by needs-based paperwork, the service-led or dependency-focus of the assessment process, performance indicators that fail to reflect outcomes, resource constraints, staff culture and attitudes, lack of regular reviews and purchasing arrangements. Furthermore, Gethin-Jones, (2012b) suggests that the outcomes-focused model necessarily brings with it a power shift away from the Local Authority purchaser affording flexibility to the provider and the consumer to dynamically modify and adapt care packages and desired outcomes to meet changes in service-users' needs. Gethin-Jones found that social workers, in their commissioning management role, have not only found it difficult to trust private providers, but have also been reluctant to relinquish their power over the service-user and to take the risks inherent in promoting service-user independence. Glendinning et al. (2008) report that the most successful implementations have been where there have been trusting relationships between purchasers and providers, and where there have been effective channels of communication with service-users in order to make these dynamic changes.

2.4 Personalisation and the funding of care

Strongly embedded within the personalisation agenda has been the concept of personal budgets (Routledge and Carr, 2013) and one which was at the heart of the 2007 Putting People First concordant between Central Government, Local Governments and the social care

sector (Department of Health, 2007). Following the introduction of the Care Act in 2014, the Conservatives-Liberal coalition Government's target has been for all users of Local Authority adult social care to receive a personal budget.

A personal budget is a sum of money that a Local Authority allocates to a user to meet their social care needs that are established through assessment. The personal budget can take various forms. It can be managed by the Local Authority, with the Authority commissioning services on behalf of the user, but involving service users in all care planning. Alternatively, a personal budget can be paid directly, either fully or partly, to the service-user's bank account as a Direct Payment with set national guidance and rules on how that money may be spent but allowing the purchase of less conventional care services for example they can also pay for a companion to support them to take part in social activities. Thirdly a personal budget can be managed through an Individual Service Fund, where the service provider works closely with the service-user to provide flexible support whilst remaining within the terms of the contract between the provider and the commissioning authority. These more flexible contracting arrangements mean that rather than sticking to a predetermined specification of care, they can make best use of the personal budget by designing, delivering and changing the support necessary to meet someone's needs.

Whatever form the personal budget takes, the first step the Local Authority will take is to carry out an assessment of care eligibility, following which it will provide the service-user with a budget based on their needs. The Authority will then work with the service-user to agree outcomes and then oversee the support planning stage, when the service-user and the care provider design the care package that best meets those agreed outcomes. Once the care package is in operation, the Local Authority will provide on-going support and carry out regular reviews to ensure that needs are being met and that funds are being used efficiently and in line with the care plan.

According to the National Audit Office (2016), in the year 2014-2015 it was estimated that there were 370,000 people aged over 65 receiving social care. Of this figure, approximately 83% received a Personal Budget with the remaining 17% having their care commissioned directly by the Local Authority. For those receiving a Personal Budget, that Personal Budget was delivered to approximately 18% through a full or partial direct payment. The uptake of the Individual Service Fund has been slow with just 4% of all service-users taking this option, with younger people rather than older people being more likely to manage their Personal

Budget in this way. This means that for approximately 82% of older people receiving a Personal Budget, that budget is still being managed by the Local Authority (see figure 3)

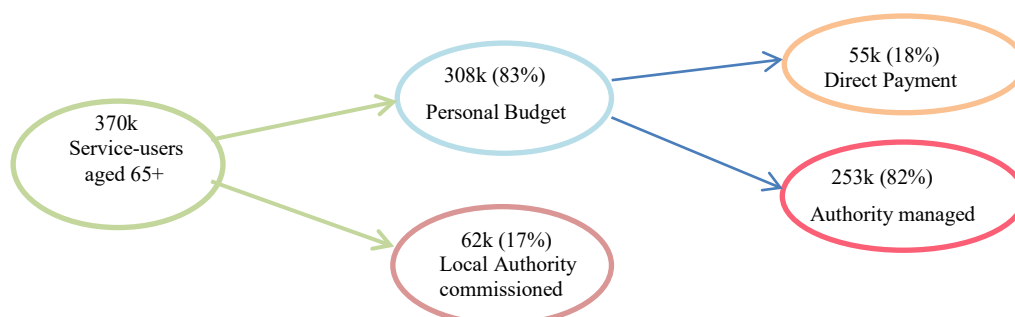


Figure 3: Number of older people aged 65+ accessing Local Authority services and using Personal Budgets in 2104-215 (adapted from National Audit Office, 2016)

With such a high proportion of Personal Budgets being managed by the Local Authority, Age U.K., (2013) question whether the full benefits of personalisation are achieved when budgets are managed by others. They challenge that a personal budget managed in this way offers far less choice and control as when managed through a Direct Payment. Furthermore, they suggest there is far less flexibility in the way in which care and support is provided, an opinion echoed by Baxter, Rabiee and Glendinning (2013).

Whilst Hasler and Marshall (2013) report positive outcomes with Personal Budgets per se', their National Personal Budget survey identified Local Authorities being more reluctant to promote the option of taking the Personal Budget as a Direct Payment to older people and that older Personal Budget holders are being directed towards managed accounts or commissioned services. The authors also suggest that Local Authorities make assumptions about how willing and able older people are to manage their own budgets. They also report that Local Authority staff are concerned about risk for older people when they can purchase their own care through the Direct Payment.

There are also concerns from the older person's perspective. The Individual Budgets pilot programme, conducted over two years 2006-2007 involving 13 Local Authorities, was a cross-government initiative led by the Department of Health that set out to gain a better understanding of how resources are allocated. In their evaluation of the programme, Glendinning et al. (2008) found that older people have lower expectations and hence under

assess their own needs. Help the Aged (2008) also suggest that older people worry about how they will manage the administrative side of recruiting their own carers, and that they would worry about recruiting strangers as carers, and what they would do if the arrangement they had set in place broke down. The Equality and Human Rights Commission (2011) also report a lack of knowledge, understanding and information provided to older people about Direct Payments.

In spite of the challenges however, 70% of those older people who have personal budgets have reported successful outcomes (Hatton and Waters, 2011) including being supported with dignity and respect, remaining independent for as long as they choose, feeling in control of their support and their lives in general, and ultimately with regard to their physical and mental well-being (Routledge and Carr, 2013). The implementation of personal budgets continues to gain momentum, albeit, in the main, by way of managed budgets for older people.

2.5 A mixed economy of care – a source of confusion

The mixed economy of care, including provision and purchasing, has created confusion for older people as they attempt to navigate their way through issues such as who is providing care, who is paying for care and what type of care they can receive (Equality and Human Rights Commission, 2011). As services change so do the individual and societal experiences, understandings and expectations of care and few older people are well-informed about how the care system works (Sykes and Groom, 2011). In the Kings Fund report (2013) Humphries reports that due to the fragmented nature in which social care has evolved, who pays for and who delivers what across the health and social care is unclear and disjointed. The lines between health care and social care both in terms of delivery and funding is indistinct with a confusing mix of NHS funding, Local Authority funding, private funding and private and public delivery.

When an older person needs help at home, finding out what options are open to them can be a challenging task when there is an array of options across the public, private, and the voluntary and charitable sectors, alongside the informal care provided by friends or family (Equality and Human Rights Commission, 2011). Deciding which service or combination of services will provide quality care and be the best fit for their needs is difficult, especially when the dealing with funding. Information is vital and yet it is not always available or easy

to understand. The Equality and Human Rights Commission, (2011) report older people, who use home care, having limited or no understanding of the domiciliary care system, including how it works, who provides it, who pays for it, what they were entitled to and what the range of options were. In their qualitative study with older people in receipt of home care, they quote older people finding the system of different services too complex and bureaucratic. They also surveyed voluntary organisations, who also reported that the information for older people about the services available to them is often scant, and when it is available it is not easy to find or access, and is frequently out of date or incorrect. In their participatory research, Ward, Barnes and Gahagan (2012) also heard older people saying that the availability of information and advice about sources of help often makes it hard for them to find the help they need. Ware et al. (2003) interviewed older service users, their carers and care managers to explore their experiences at the operational level of arranging, delivering and receiving care services. Older people reported having insufficient information about the care services available to them to allow them to make an informed choice, and some found it difficult to know what to ask for without first knowing what services are available. Baxter, Rabiee and Glendinning (2013) stress that whilst the current policy is to provide users of social services with greater choice, it is imperative that to be able to make informed choices, people need access to information about the opportunities available to them and, furthermore, that information should be “understandable, relevant and high-quality” (Rosen et al., 2005, p. 18). However, in 2012, the Health Select Committee Enquiry Report on Social Care concluded that social care services were not only fragmented and wasteful but also confusing (House of Commons Health Committee, 2012).

Not only is there confusion surrounding the services that are available, but the financing of care is complex (Lloyd, 2013) and has evolved in a piecemeal manner from a combination of NHS, Local Authority and social security fiscal systems that each have their own interests at heart. The NHS system is provided free at the point of delivery, but Local Authority funded services are means tested. However, understanding what constitutes health care and what constitutes social care is unclear, for example rehabilitative care following hospital discharge. This is epitomised in Twiggs’s ‘Deconstructing the social bath’, (1997), which reports how community nurses refused to give a bath, classing it as a social and not a medical bath. Add to this the issue of Local Authorities now being the main purchasers of care with only a minority of them being also the providers, and now the co-ordination and integration not only presents management with a major challenge but also causes even more confusion for the

older person when trying to decide upon the best package of services, when they have typically expected their home care to be free like their health care (Phillips, 2007). Eligibility criteria are getting stricter with, in some cases, the withdrawal of funding for care to meet moderate need and the abandonment of preventive care (Age U.K., 2014).

It has also become increasingly difficult to balance formal care, typically that which is paid, regulated and monitored, with informal care which is in the main, provided by family and friends. More stringent eligibility criteria have resulted in reduced funding for formal care. The Personal Social Services Research Unit estimated in 2010 that 800,000 people aged 65 and over in England had unmet care needs (Forder and Fernandez, 2011) and in 2014, 87.5% of Local Authorities no longer fund care for older people with moderate care needs (Age U.K., 2014). With the changing of family demographics, what may have been available as informal unpaid care may be no longer available. Not only are women increasingly participating in the labour market, but parents are more and more becoming the ‘sandwich’ generation (Smith, 1989). They find demands on their time coming from older children as they return to the family home which in turn compromises the time they have available to provide informal care to their parents (Milligan, 2009).

2.6 Eligibility criteria and unmet needs

Against this backdrop of complexity, confusion and change, community based research has identified a large number of older people living with unmet needs, such as getting help to get out of bed, to wash and dress, to prepare food and with toileting (Age U.K., 2017). Exploring whether this can be attributed to real or perceived lack of resources, or reluctance on the part of the older person to seek help, the authors found that for some older people there was a degree of low motivation and a disengagement and withdrawal from society in preparation for the end of life. However, whilst they found that some older people reported a lack of information, some report declining or withdrawing from inadequate, inappropriate and rationed care services. Cordingley et al. (2001) report unmet needs due to reluctance on the part of older people to burden their family or friends, a need for self-reliance autonomy and independence, and ageist homogenising attitudes on the part of professionals to their physical and mental ailments.

The assessment process has been criticised for focusing too much on deficits and problems, and not enough on potential and positive outcomes (Miller, 2010). Before the implementation

of the 1990 NHS and Community Care Act, assessment procedures were service-led, where people were slotted into a restricted range of fixed and traditional services, and there was little attention paid to specific needs of the individual with simply age or impairment being the rudimentary measures used to allocate care (Parry-Jones and Soulsby, 2001). However, the new Act introduced the needs-led assessment that was promoted as the way to achieve personalised and tailored care as opposed to prescriptive and service-led solutions. Yet focusing on needs has proved a challenge against a backdrop of austerity and a growing older population, that has brought with it a rationing of services and rising of eligibility criteria, (Abendstern et al., 2008). It has meant that in order to ensure the older person meets the eligibility criteria there is an over-emphasis on those problems and deficits that highlight risk, and an under-emphasis on the person-centred and personalised issues such as goal-setting and outcomes.

Furthermore, the spiralling growth in the number of older people in receipt of formal home care packages has been accompanied by an increasing complexity in the type of work that is carried out by carers. Whereas in the early days, care was targeted at supporting people with domestic tasks, now responsibilities typically include bathing, dressing, toileting, shopping and preparing meals, as well as traditional nursing activities, such as changing catheters and administering medication. As assessment of needs and eligibility criteria has become more stringent and domestic tasks have been sacrificed, preventative tasks such as cleaning, shopping, transport and providing opportunities for leisure activities are only provided to those with the most complex array of needs. Yet domestic tasks prove challenging for some older people with a significant number being unable to get their shopping or clean their homes (Godfrey et al., 2000). Windle et al. (2009) suggest that this low level preventative service is increasingly provided by the voluntary sector. However, in 1996 the House of Commons warned that denying such support would reduce feelings of well-being, inclusion and independence and “it is potentially counter-productive for authorities not to invest in preventative services” (cited in Wistow and Hardy, 1999, p.177). Nevertheless, in 2017 Age U.K., (2017) reported that those with moderate needs were left with no support at all; 87.5% of Local Authorities were no longer funding care for older people with moderate care needs for example needing help with getting out of bed, washing, dressing, preparing meals and toileting

2.7 Today's landscape of care

As part of the drive for managerialism and marketisation, and to increase competition and consumer choice, the 1990 NHS and Community Care Act gave responsibility to Local Authorities to commission private domiciliary care services that would compete with their own in-house services. As a consequence, by 2012, 81% of domiciliary care hours were delivered by private care providers with the number of hours being provided by Local Authorities in steady decline (United Kingdom Home Care Association, 2012). Glendinning (2012, p.294) suggests that whilst there are a significant number of monopsony contracts, the provider market is “fragmented, unstable and diverse”. The turnover of providers is increasing and the United Kingdom Home Care Association, (2016) express growing concerns about the instability in this market. United Kingdom Home Care Association evidence that a growing number of providers are surrendering their undeliverable contracts back to Local Authorities, with fears about the sustainability of their business. Ensuring services continue in such a climate proves problematic for Local Authorities. (Wistow and Hardy, 1999) suggest that some older people are not interested in which provider delivers the services since they are more concerned that care on a day to day basis is of a high standard and that there is a reliability and continuity of carer. Yet meeting these needs is also a challenge. Having regular carers is difficult to achieve when the turnover of staff within the home care sector is high (United Kingdom Home Care Association, 2016). The turnover rates across the independent and voluntary domiciliary care sector England increased from 24.3% to 39% between in 2015 and 2016. Domiciliary care work is typically characterised by poor pay (with many care workers being paid the minimum wage), zero hours contracts, lone working, high workload, and poor training and having a high level of responsibility (McClelland and Holman, 2011). These factors have a direct effect on staff recruitment and staff retention, which in turn has an effect on the reliability and continuity that older people seem to value.

With regard to pay, the Care Act of 2014 stipulated that Local Authorities must:

“assure themselves and have evidence that service providers deliver services through staff remunerated so as to retain an effective workforce. Remuneration should be at least sufficient to comply with the national minimum wage legislation.” (Care Act, 2014, cited in Hayes, 2014, p.3).

Regulations also stipulate that carers must be paid for time travelled between service-user's homes, a practice that previously many agencies avoided. This often resulted in carer's pay equating to far below the minimum working wage (McClelland and Holman, 2011).

Poor training was an issue raised by the Equality and Human Rights Commission in their homecare study, (2011). They evidence that when carers lack core skills, the human rights of older people is in jeopardy. The written and verbal skills of migrant care workers was an issue, if they were unable to communicate effectively due to a poor command of the English language. Although conversely, there were reports that those with a poorer command of the English language had better results with people with dementia as they concentrated harder to understand. Nevertheless, the report emphasises that lack of basic training across the board was negatively impacting the well-being of older people. However, in July 2013 the Cavendish review proposed that all healthcare assistants and social care support workers must follow the same basic training in order to obtain standard 'certificate of fundamental care' before being allowed to care for people. Hence, since the implementation of the Act in April 2015 all care staff must obtain the new Care certificate. It is expected that this certificate will address inconsistencies in training and competencies across the workforce. Care staff will have the same introductory skills, knowledge and behaviours in order to provide the safe, high quality, compassionate care that reports such as that of Equality and Human Rights Commission, (2011) call for.

At the heart of the 2014 Care act is the well-being principle. The Act requires that Local Authority, when delivering care, must promote the individual's well-being considering the following 9 principles:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over their day-to-day life (including control over care and support provided and the way they are provided)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal domains
- suitability of the individual's living accommodation
- the individual's contribution to society (Care Act, 2014).

These well-being principles place the service-user at the heart of services and reinforce the personalisation agenda that was promoted by earlier Governments. Rather than service-users having to fit into the services that are available, now social care must tailor around the needs of the individual.

In this age of austerity it is yet to be seen how the Care Act of 2014 affects the purse of the Local Authorities. It brings increased costs by way of increasing overheads, higher eligibility thresholds thus potentially greater financial support for service-users and an increase in the number of care assessments (Allan, 2015). Whilst the Government allocated funds to cover these costs, there is concern that demand for, and thus the costs of assessments may have been underestimated (National Audit Office, 2015). The Care Quality Commission has warned that pressures on Local Authority budgets created by the Care Act 2014 is likely to seriously impact on the extent to which care providers are able to maintain, let alone improve the quality of their care (Care Quality Commission, 2015).

2.8 Summary

Understanding who delivers care is difficult in a mixed economy, and sometimes an older person may be unsure about whether care is coming directly from the Local Authority, from a care agency, or via the third sector. Add to this the changing eligibility criteria and it is not only a question of who provides care, but the amount of formal care funded by the Local Authority changes in line with the latest economic measures. The type of care, whether it be task centred or outcomes-focused is dependent on where the older person lives, and their own Local Authority's approach to care delivery. Adding to the complexity is the opportunity to personally manage the budget allocated by the Local Authority and to understand the implications of direct payments or a managed budget.

Figure 4 provides a timeline showing milestones in the development of domiciliary care and the above discussion highlights the many complex contexts in which care is delivered and the boundaries that can exist between older people and the care commissioners and the care providers.

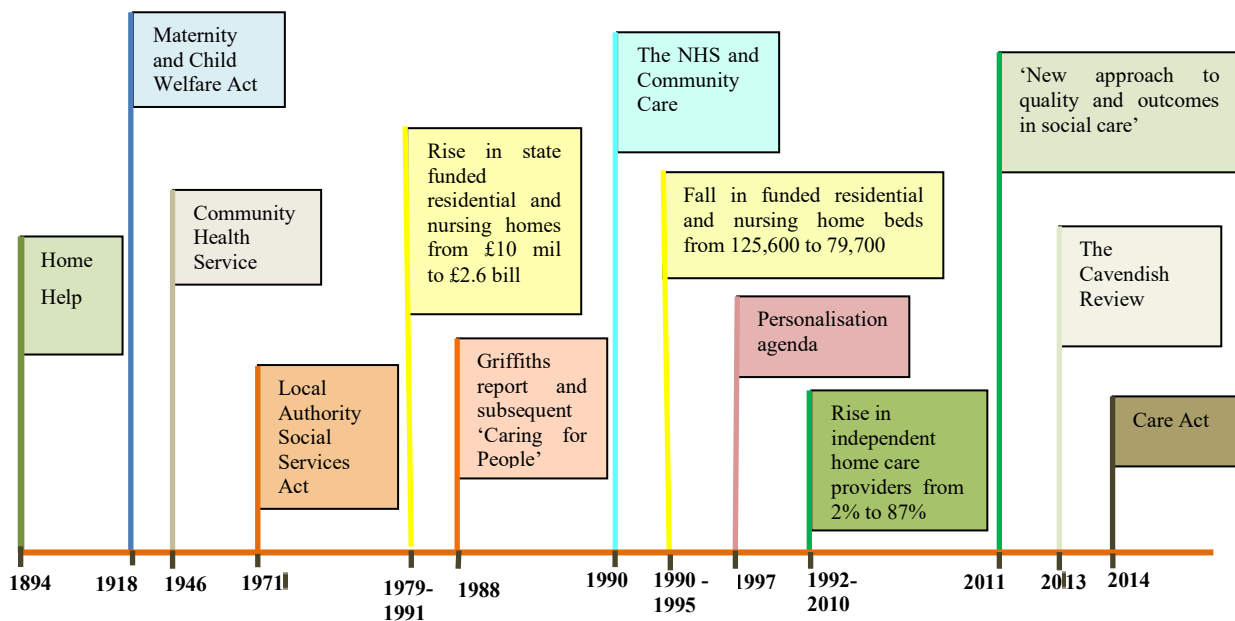


Figure 4: The evolution of domiciliary care services and the policy context

The drive for care in the community has dramatically changed the face of care for older people over the last forty years. With the drive for personalised care that seeks to promote independence well-being choice and autonomy, has come a shift of responsibility from the state to the individual. In modern society, dependence has become a negative trait whilst independence, personal responsibility and self-sufficiency have been the qualities to which we must aspire (Aronson, 2002). Yet with a growing older population, greater Local Authority austerity and more stringent eligibility criteria, an increasing number of older people are being left to their own devices without support with basic acts of daily living. When once the state would have been held responsible for the physical and social health and welfare of the older population, the political emphasis is on individual agency away from dependence on welfare. Some older people welcome the chance to remain in their own homes surrounded by and connected to their personal narratives and histories. Yet it is questionable the degree to which an older person who needs care at home is able to exercise agency over the care they receive whilst it is determined by the current political and economic forces. This research seeks to understand how, within the current context of care, older people's selves are respected and sustained. How much does the current climate of care affect an older person's identity or "that aspect of self and personality which expresses the overall unity and purpose of an individual's life" (Coleman et al. 1998, p.391)? The concept of identity is a complex

and contested one, and in attempting to answer this question I explore, in the following chapter, different understandings of the terms self and identity.

Chapter 3

A Review of Literature

This chapter includes a review and critique of literature that explores the experiences of older people, focusing on the concepts of self, identity and ageing and within the context of domiciliary care. It could be considered a more traditional review (Pope et al., 2007) in that the literature explores key theories and ideas, providing a broader context to the research, as well as synthesising relevant empirical studies.

Firstly, with the concept of self and how it is maintained in the context of domiciliary care being at the heart of this research, the review explores what is meant by the term 'self'. Looking through both the lens of life stage theory and symbolic interactionism it analyses how each offers up ways to understand the construction of self.

The review then goes on to examine literature on ageing theories, considering how the older person understands and interprets the ageing process and how, at the point of care delivery, ageing is understood by carers and care organisations and the implications for care practice. This is complemented by a discussion on the ways in which external political and sociological factors influence the way in which people experience ageing and being cared for.

Finally these conceptual understandings of care, ageing and self are used to look at what is known so far about what promotes and supports or adversely affects self within the domiciliary care setting and the extent to which care practices meet the psycho-social needs of older people. The review examines how domiciliary care practices respect individuality, how important autonomy is for an older person as they may lose control of their home and their body space and how such factors can contribute to loss of dignity and of sense of self. It then looks at how different models of care delivery affect the care experience, and, more specifically, how older people feel about such matters as the timing of calls and the regularity of carers.

The literature search

The search of the literature included key word searches of relevant electronic databases, an examination of the grey literature including research reports using relevant websites, and theoretical readings, including those recommended by my academic supervisors from the

Faculty of Health and Social Care, and Education, Anglia Ruskin University. Furthermore, rather than relying solely on pre-defined search terms, criteria and protocols, the evolving search (Bates, 1989) also followed a process of “berry-picking” (Barroso et al., 2003) and employed a diverse range of strategies including reference snowballing (Booth et al., 2016), electronic citation tracking (Greenhalgh and Peacock, 2005) and author searching (Bates, 1989).

Inclusion and exclusion criteria

The inclusion criteria were set as:

- All literature irrespective of date of publication in order to understand the historical and current perspectives with regard to care for older people
- Papers published up until November 2017, including papers published online ahead of print versions published at a later date
- Books that report on conceptual and empirical work
- Academic research reports that present conceptual and empirical work
- Grey literature
- Dissertations, theses and conference papers
- Documents that have a focus on older people (aged 65 years and over)

The exclusion criteria were set as:

- Documents published in languages other than English

The searches returned a wealth of literature pertaining to the care of older people with dementia. However, since I was unable to include participants to the study with significant communicative/cognitive impairment, this body of literature was outside the scope of the study and was excluded from the study.

Keyword search of electronic databases

The following journals were identified as being relevant to this area of study:

- Academic OneFile
- ASSIA (Proquest)

- JSTOR, Psychology & Behavioural Sciences Collection
- SCOPUS (Elsevier) Social Care Online
- Social Policy and Practice incl. Child Data
- Social Services Abstracts, Sociological Abstracts
- Web of Knowledge
- Wiley Online Library
- Sage

The following search words were entered into these journals (Taylor et al., 2007)

(“domiciliary care” OR “home care” OR “home-care” OR “community care”)

AND

(aged OR elderly OR older OR senior OR old OR “older person” OR “older adult” OR ageing OR “getting old” OR “advancing years”)

AND

(identity OR identification OR personality OR dignity OR autonomy OR integrity OR character OR “well-being” OR “well being” OR “quality of life” OR character OR self OR “sense of self”)

Sources of grey literature

Included the following:

- Social Care Institute for Excellence.
- Joseph Rowntree organisation
- Age U.K.
- King’s Fund
- Personal Social Services Research Unit
- Department of Health

Assessing relevance to study

Once duplicate references had been deleted, the first stage in deciding whether to include or exclude articles included a title and abstract review. Fully-refined searches generated results that were clearly irrelevant to the research questions and an examination of titles and abstracts was necessary to begin to filter out irrelevant writings.

The second stage involved examining the full text of remaining documents to establish relevance to the research questions. Texts that still fulfilled the inclusion criteria were included in the final review sample (see Appendix 8, PRISMA flow chart for a summary of

the review process). At each step of the review process, included references and documents were imported into the bibliographic management system RefWorks.

The review now commences with an exploration of the concept of self. Taking the social constructionist position it looks at how symbolic interactionism and role theory contributes to an understanding of the factors that influence who a person is and their identity with others. However, it also consider the more reflexive, introspective understanding of self, and taking life stage theory, looks at how previous life experiences influence the self now.

Looking through both lenses the review allows a better understanding of the factors that influence the older person's experience of care.

3.1 Self and identity through the later stages of the life course

Central to this study is the concept of self and how it is maintained when an older person, who may no longer be able to independently manage activities of daily living, receives care in their home. When they need domiciliary carers to support them with very personal and intimate activities such as bathing, dressing, preparing meals and getting into bed, older people can find that their privacy, dignity and autonomy depends on how this help is delivered. As mentioned in the introduction, my interest in this research began when I worked as a domiciliary carer with older people. I met several older people among who was a 94 year old lady, Mary who made the strongest impact. She was blind and deaf, could not walk unaided, and was in receipt of care four times a day to assist with toileting, bathing, dressing and feeding. Mary was a proud lady who had taken great pride in her appearance and valued her personal privacy and dignity. I took great care during personal care to protect these values for Mary, making sure she was as comfortable as she could be throughout this very personal act of care. When I first met Mary I had no idea of the person I was caring for. I initially saw her as a 94 year old lady with several physical limitations, and I cared for her as instructed through the care plan using a task-based approach. I later realised that in using this method of care I had missed opportunities for Mary to share her delightful self. As I grew to know her, however, I realised her wizened body and physical decline masked her inner vivaciousness. Such animation and energy is something that is not generally associated with older people (North and Fiske, 2015). Featherstone and Hepworth (1989) introduced the concept of the mask of ageing in that the physical signs of ageing mask the true feelings of the person underneath, a matter I explore further in section 2 of this review. I saw Mary through the

mask of an old lady and initially failed to see her inner energy. She loved to laugh, tell jokes and recall stories of times gone past. She had also been a wife, a mother a grandmother and great-grandmother and had lived in her home for more than 60 years. I learned that she had very strong family values and loved to tell me all about her brood, showing me photographs as I worked. I encouraged this interaction as I knew it made her feel happier and she looked forward to my visits. However, when I no longer worked as a carer and I returned to visit her as a friend, I witnessed care that was very different. Carers made no effort to communicate with Mary. They seemed to go about their care duties with no connection to Mary's wonderful self. I could see Mary's sadness and sense of isolation as she played no part in the communications going on around her. I began to reflect on the role that self plays within this caring dynamic, how much care considers the individual, and whether this matters to people receiving care at home. Furthermore, I reflected on the consequences for older people if their selves are disconnected from the care they receive. This reflection led me to ponder the concept of self and I thought about whether self changes as a person goes through their life transitioning into different environments, particularly as health declines and they need support from others. Tanner (2001) suggests that the limitations of age, along with physical demise, can impact on the sense of self and any consequential loss of independence can bring about a "struggle, in the face of inimical forces, to preserve continuity with existing concepts of the 'self' and, at the same time, to preserve an acceptable social façade" (p.268).

A predicate to an exploration of these potential effects is an understanding of what is meant by the terms self and identity that are used frequently and interchangeably in such discussions. Yet they are concepts that are not easily grasped (Reynolds, 2003). Across literature there are multiple and frequently inconsistent definitions. Psychodynamic theorists believed that personality was established and fixed in the early years of childhood (Caspi and Roberts, 2001), whilst Erikson suggests that self develops as we move through the stages of our development. Symbolic interactionism, beginning with Mead (1934) introduced the concept of role identity. Further developed by Stryker (1968), role theory states that one has multiple identities throughout their lives, depending on the role that they play, even perhaps switching dynamically between identities to suit the environment they are in. At any given moment and depending on the social context, one version of self is beckoned whilst others are repressed. There is no universal understanding, and in the next section I explore the literature considering how the concept of self has evolved over time

3.1.1 Self - an elusive concept

The nature of self has been at the centre of philosophical debate for centuries. It is presented in both classical and contemporary literature in many semblances, spanning various domains including those of the psychoanalyst, the psychologist, the political scientist, the anthropologist, the sociologist, and the historian (Gallagher, 2000). The ancient philosopher Heraclitus of Ephesus (530-470 BC) postulated that everything in nature is in a state of flux and “In the same river we both step and do not step, we are and are not” (Heraclius, B49a cited in Baird and Kaufman, 2007). However there are two aspects to this analogy. Firstly, no context ever persists; it is always in a state of flux. There is nothing in the world that is consistent and static and that we can declare to be a definite, unchanging truth. Secondly, not only does the river change but so do you, and when you step in and out of the river you do so as a different being. A century later Plato applied this to the human condition and postulated that, like the river, a person’s spiritual being cannot remain the same over time and that not only is the body constantly changing but so is the soul (Plato, 207d-207e cited in Reeve, 2012).

Plutarch's ‘Theseus paradox’ also questions what it is that makes us who we are. As each plank of the ship is removed, the ship still seems to intuitively maintaining its identity, but if more pieces were to be removed it no longer remains the ‘Ship of Theseus’, instead it becomes a pile of wood that once was a ship. At some indiscrete time during the deconstruction, it moved from existence to non-existence. If ‘The Ship of Theseus’ can only be identified by its individual parts then as soon as the first part was removed it was no longer the same ship . Moving away from the metaphor into the matter in question, the paradox illuminates the question of what makes us who we are. On a physical level, it is not possible to claim you are the same person as when you were born, when over the course of approximately fifteen years human cells are completely replaced (Vince,2006). Similarly, if you lose a limb or shave your head, or, more pertinently, if you become old and frail and need care you may take on a new identity and others may see you as a different person. Whilst you may still feel the same on the inside, to others you may appear different.

Moving forward in time, the idea of self was introduced into seventeenth century Western conscious thinking by Descartes. He provided philosophical proof of existence based on the fact that someone capable of any form of thought necessarily exists. Thought exists and because thought cannot be separated from me, I must therefore exist, or as he famously and

more succinctly expressed it, "I think, therefore I am" (Descartes, 1637, cited in Thomas and Wardle, 2014). William James, in his seminal work *Principles of Psychology* (James, 1890, cited in Johnson and Henley, 2013), explored the consciousness of self, distinguishing the empirical known self 'me', from the abstract knowing and spiritual 'I'. James classified the 'I' self as the pure ego, the thinking self, the soul. It is the part of self that provides the continuity throughout life's journey, acknowledging how our individual identity threads through all experiences in our past, present and future. He saw the empirical 'me' being represented in three ways: the material self, the social self, and the spiritual self. The material self consists of things that belong to us for example our bodies, our physical possessions or things that we belong to including family, social groups. The social self represents how we manifest ourselves in different social situations, perhaps adapting our behaviours according to the needs of the moment. The spiritual self is who we are at our core, our inner or psychological self and pertains to those characteristics that persist through time. It is only through deep self-examination and reflection that one can know the true spiritual self without distractions from the material or social self. James' theory has foregrounded the importance of self for understanding human action. A number of eminent philosophers including Kant and Freud have debated the concept of individual introspection and inner perception through the ages with the twentieth century finding several influential theorists placing the importance of the self at the centre of understanding of human behaviour.

It is important at this stage to understand the differences between the terms self and identity and how they are used in the context of this study. The concepts are quite distinct (Owens, 2006) and yet the terms are frequently used ambiguously (Swann and Bosson, 2010). The words appear frequently within common language, for example 'self-esteem', 'self-awareness', 'sense of self', 'be true to myself' and 'identity theft' 'sense of identity', 'identity crisis'. Owens (2006), recognising the need for clarity, defines the terms as such:

Self: "an organised and interactive system of thoughts, feelings, identities and motives that (1) is born out of self-reflexivity and language (2) people attribute to themselves and (3) characterise specific human beings" (p.206)

Identity: "categories people use to specify who they are and to locate themselves relative to other people" (p.207).

As shown earlier theologians and philosophers have wrestled with the question 'do I exist?' focusing on the more introspective view of one's own being. Cooley, taking James' theory further, developed the idea of empathic introspection. There is an interaction between how

others see us and how we see ourselves, and we build, change and maintain our self-image based on the perceptions of others. Through this 'looking glass self', Cooley crashed down the barrier that Descartes had built between the individual and society theorising that "There is no sense of 'I' without its correlative sense of you, or he, or they" (Cooley, 1998, p.163).

It is this movement away from the idea that self is understood through pure introspection that now helps one to understand how identity is placed. The more extrospective view of self is that it comprises a relational property. Not only do I have my own unique characteristics, but the way in which I locate myself with others provides me with a sameness, a relatedness, an identity. Thus someone's identity is socially constructed and

"that part of an individual's self-concept which derives from his knowledge of his membership in a social group (or groups) together with the value and emotional significance attached to that membership" (Tajifel, 1981, p.255).

It follows then, that within one's self there can be multiple and at the same time simultaneous identities. There can be that of mother, neighbour, worker, friend, athlete, activist and "there can be as many different selves as there are different others that can recognise the individual" (James, 1890, p.294, cited in Johnson and Henley, 2013). Furthermore, each identity brings with it a set of practices, roles and beliefs that are recognised by others (Leary and Tangney, 2012). Placing this discussion in context, let us consider an older woman who has regular carers visit her at home. She is also a mother, a friend and a grandmother. The cared-for role may call upon personal traits such as resentment, frustration, anger, envy or joy, engagement or confidence. Alternatively, when the grandchild visits, the grandmother role may induce characteristics such as protectiveness, playfulness, love and care or even impatience and irritability that can be felt when cared for as well. Each of these roles and their attributes prompt behaviours that are congruent with that role. Different roles may share characteristics, for example playfulness as friend and grandmother, or frustration as mother and 'cared for'. Thus, features of the self have the potential to change as the contexts and the relationships change and so identity does not represent solely the individual construction of self, but also social construction of self.

It seems that the terms self and identity mean something different yet they are connected. Self seems to pertain to the more introspective being, whilst identity is more about how we are placed within the context of others. Considering the older people I cared for, I have reflected on how much their selves might have developed through their lives, and furthermore how the

roles that they enact now affect who they are and how they experience the care they receive. I explore these two very different ways of looking at a very similar concept and analyse how an understanding of both can inform care practice. Firstly, I will focus on the nature of identity from a sociological perspective, in that identity is forged in the domain of the social, and is never just an individual matter in that it is “shaped by our experiences, relationships and interactions” (Scott, 2015, p.1). Since care takes place within a relational context, the theory of symbolic interactionism and the relational view of the self can develop and understanding this how older people adapt to being in a position of care.

3.1.2 Symbolic interactionism and identity theory

Whilst James introduced self into the arena of psychology, the positivist drive for empirical evidence meant that it failed to gain recognition within the eminent schools of psychology. It was the likes of the sociologists Cooley and Mead that took up the gauntlet. In his seminal text, ‘Mind, Self and Society’ (1934), George Mead, building on the foundation of James’ pragmatism and, influenced strongly by his colleague Cooley, provided a profound account of human behaviour, consciousness and sense of self that some claim laid the foundation for the sociological theory of symbolic interactionism (Brinkerhoff et al., 2013). At the heart of this theory is the idea that the self is socially constructed through linguistic and other symbolic exchanges with others. It does not exist at birth and does not evolve through a process of biological development.

The three fundamental tenets of symbolic interactionism are meaning, language and thought (Blumer, 1986). Firstly the way that people behave towards others is determined by the meanings they have for those others. Secondly, the language of social interactions provides the source of those meanings. Finally, identity is developed through reflection and interpretation of social worlds, and through seeing oneself from the perspectives of others. It follows then that self can only be realised within a nexus of others, and it is in this social network that self, through the identity with others, emerges, develops and is sustained. Fischgrund (1975) proposes that identity can only be constructed in the context of group affiliation and solidarity. Placing this in the context of care, Janssen et al. (2011), in their qualitative study with older people receiving care in the community, report participants placing great importance on mutual responsibility and solidarity. In spite of their own difficulties they felt empowered by their ability to help others and being part of the community was a source of strength. Being able to interact with others, apart from just

family, gave them a sense of agency, and a feeling that they were meaningful to others and part of a whole beyond their own home. On the other hand participants also reported the surprising positive societal response to their age and frailty as being a source of strength. They talked of the value of warm, empowering relationships with not only family but with care professionals. They reported that commitment, reliability and interest were significant characteristics of the care relationship. Abad-Corpa et al. (2012) stress the importance of a positive care relationship, and suggest that caregivers who adopt a holistic and strengths based model of care encourage feelings of self-esteem, competence and self-worth. Hvalvik and Reiersen (2011) also report the value of positivity and encouragement, but do warn of the power and control that some carers can exert by stifling the older person's autonomy and not taking full advantage of their positivity and strong desire to manage.

Stryker (1968) takes symbolic interactionism further by developing Role Theory, proposing that the positions that people situate themselves within their social network carry the conventional behaviours and expectations that are their roles. Furthermore, roles carry with them expectations about how people should enact these roles and communicate with others. Stryker introduced the notion of 'salience hierarchy'. In a situation without structural constraints, for example when joining a newly established group, the individual has a choice about which identity or range of identities to embrace. As security within that group gains momentum and structure, the salience hierarchy will play a greater part in determining which identity is called forth. The more commitment an individual shows to an identity, the higher it will be on that hierarchy and the greater its salience. As the adopted identity is more positively valued by others and mutual dependence grows, the stronger the identity grows, resulting in enhanced congruence between role expectation and role performance, and consequently promoting feelings of self-esteem. Unlike traditional symbolic interactionism, and perhaps returning to James' original view of a less ephemeral self (Swann and Bosson, 2010), Stryker focussed less on how identity is achieved through the reflection of how others see us. Rather, he saw identity as being socially constructed through the roles that are played out, with each role bringing forth a role identity. Through labelling ourselves as belonging to particular social categories, we build our own self conceptions and attribute meaning to ourselves. Identities are developed and maintained within the role relationships.

However, old age is frequently experienced with physical, sensory, cognitive, social and economic losses as associated resources shrink (Kaufmann and Elder, 2003). Furthermore,

the changes related to ageing may result in role loss as it becomes more difficult to tolerate multiple activities associated with multiple roles. This in turn can be responsible for social disengagement and lower levels of life satisfaction (McKenna et al, 2007). Christiansen and Baum (2005) suggest that if an older person is able to maintain roles, then their level of life satisfaction will be maintained.

In conclusion, the symbolic interactionists', and in particular the role theorists' understanding of the factors that influence who a person is and how they respond, has much to offer in the understanding of how older people adapt to being in a position of care. Whilst the sociological understanding of identity comes from looking at influencing factors coming from outside the individual, who a person is can also be understood from taking a more internal, introspective view of the self (Ross 1977). Understanding self extends beyond seeing the individual as a social actor, but may also come from a reflexive understanding of how the past self has developed into the self now and how in turn the present self will evolve to the future self. I now explore life stage theory to gain a better understanding of how an older person's life experiences contribute to their experience of care.

3.1.3 Life stage theory

As shown above, the sociologists' view is that there is a 'social self' that it is realised through interaction with others and that these identities are developed and sustained through role relationships. (Gove et al., 1989). Yet theories of human development support the idea that psychological development occurs in a sequence of stages and that one is born with a predisposition to certain personality traits. Erikson's life stage theory (1963, 1968, 1982) describes these stages as the eight ages of man with his wife Joan later adding a ninth stage. The psychosocial development of the ego unfolds in an epigenetic succession of eight stages over a lifetime, where each stage has characteristics that differentiate it from previous or subsequent stages. The transition into a new stage presents disequilibrium and a new psychosocial crisis with an increase in both potential and vulnerability, and the ego strives for mastery of the environment. Ego qualities and ego strengths can flourish or flounder. They may develop when these crises are successfully resolved. However, if the stage is poorly managed then feelings of inadequacy will ensue and the ability to successfully navigate through later stages is reduced affecting the health of the personality and the sense of self.

However, it is important to recognise that these stages progress in a cumulative and not a linear manner. Even though ego qualities and strengths may be achieved through overcoming life's challenges, the battle is won but the war continues and the ego "to remain psychologically alive must resolve these conflicts unceasingly" (Hamacek, 1990). Moreover, whilst Erikson indicates a polarity in his description of the 8 stages, for example integrity versus despair, the 8th stage, he did not see it as a battle where one side must win. The tensions inherent in these stage struggles are necessary for personal development and it is through these tensions that a person develops into an integrated and complete being. Erikson's wife, in her own writings suggests that "It is important to remember that conflict and tension are sources of growth, strength, and commitment" (Erikson and Erikson, 1998, p.106). It is the resolution of the conflicts inherent in the stages of development that allows the person to emerge with a feeling of unity within oneself, good judgment and a greater capacity for success.

Erikson saw development taking place in a context of many different and significant relationships (Erikson, 1982) and being very much grounded in cultural and social environments. He was keen to explore how an individual's development is shaped by the practices of the society in which it is taking place (Engler, 2013). Consequently, and following criticism, he extended his cross-culturally empirical studies to the marginalisation of the Sioux and Yurok Indians of South Dakota and California, and furthermore to the apartheid segregation of the black African Americans. In spite of his cross-cultural studies, his life stage theory has been challenged for its universal, fixed and sequential approach to development. Its critics argue that development takes place not only within a range of diverse cultures, but also across different eras and environments that offer up varying opportunities and constraints for psychosocial development (Riley, 1978). Not only do historical and social changes mean that one generation's life experiences are different from that of another generation, but an array of biological, economic, social, demographic, and cultural factors influence the social timing of life's transitions. (Gitterman and Germain, 2013) Jepson et al. claim that when examining the concept of the life course, it is the typical life pattern that is usually the chosen model. They assert that researchers must consider deviant atypical journeys in order to extend their understanding of how people negotiate their way through life. Abeles et al. (1980) claimed that major transitions such as marriage, childbearing and even death may occur earlier for those who occupy a lower socio-economic status. The fluidity of age timetabling also impacts on how identity is developed. The age at which

people marry, buy a house, have children and retire has changed dramatically over the last 50 years (Gilleard and Higgs, 2005). Similarly, traditional sociocultural norms for gender roles are challenged by new generations with recent decades seeing the exchange of traditional roles in families and in the workplace (Ellman and Taggart, 1993).

With regard to the differences between the genders, Erikson (1968) claimed that development patterns are different. For females, development depends less on autonomy and more on intimacy and relationships. For males, however, development is more connected to separateness and independence. This view is supported by Rice who claims that “a woman’s identity is often defined through relationships and caring for others” (1989, p.248). Jacobs claims that it is through their “connectedness” that women define themselves (1990, p.27). However, one of the strongest criticisms of Erikson’s life stage theory has been from the feminist movement. Gilligan (1987) reasoned that development for girls and women relies more on the expression of love, loyalty and nurture through relationships. Yet the difficulties they experience are due to a fine balancing act between achieving autonomy whilst remaining connected. She argues that this battle is not reflected in Erikson’s life stage model. He looks through the male lens, using such words as autonomy, industry and initiative, insisting that development can only be achieved through separation. For him, attachment is an impediment to the development of identity

My research explores the experiences of older people who receive care in their homes due to physically limiting conditions, and I was particularly interested in Erikson’s views on development when there is a disabling condition. I found that, in the same way that discussions on racial difference were overshadowed by ethnocentrism, Erikson’s theory of identity development takes on an ableness position. There is limited focus on how it progresses for those with disabling conditions. His eighth stage, pertaining to older adults, is ego integrity versus despair, a stage when one is working towards accepting one’s life as being meaningful. The older person who reaches ego integrity looks back on their life with satisfaction, and death is seen as an integral part of that life. However, without this acceptance of the meaningfulness of life the older person feels despair, bitterness, and a fear of death. Yet reaching a point of acceptance and ego integrity can be a challenge for an older person with physical limitations who is in pain, suffers the isolation of being house-bound, and struggles to maintain a sense of autonomy and dignity. Similarly, attitudes and beliefs of others can have an impact. Individuation and ego-integrity can be a challenge in the later

years when even at any age a person with a disabling condition is frequently defined by their condition and their disability becomes their master status (Smart, 2001). Against a backdrop of a proliferation of the aged population, Erikson began working on a 9th developmental stage but did not publish his works. Following his death in 1998, his wife Joan completed the work using his notes and her own research observations. She claims that the 9th stage is a time of physical and mental limitations and “old age in one’s eighties and nineties brings with it new demands, re-evaluations, and daily difficulties” (1998, p. 105). With the increased loss of physical and mental abilities, the older person mistrusts themselves and the environment. Consequently, the 9th stage is characterized as “mistrust vs. trust”, ironically the same name given to the infancy stage, yet the dystonic takes precedence. Despair and resentment follow when the older person mistrusts their own body to perform acts of daily living, and mistrusts their environment to support their needs, unsure of whether care will be dependable, reliable and trustworthy. Feelings of autonomy are eroded and often older people lose their sense of place. For those who receive domiciliary care, their home can become a work place for carers and may be filled with support equipment. Furthermore, they no longer have an ascribed role to play when they do not work, and their active involvement with family diminishes. Joan Erikson claimed the 9th gerotranscendent stage was a time for redefining one’s perception of life and death, having a reduced fear of death, and losing interest in needless social interaction and material possessions. She prescribed an attitude of acceptance of one’s limitations and the resignation to the inevitability of death and “to face down despair with faith and appropriate humility” (1998, p. 106).

The transitional stages are central to Erikson’s theory, and as one progresses through each of the stages, one is presented with a range of challenges and tasks that may be confronted (Erikson, 1982). Furthermore, the outcome of coping well with these tasks will be a clear sense of self. Old age can bring with it feelings of loss, fragility, vulnerability and unpredictability (Snodgrass, and Sorajjakool, 2011) along with physical and cognitive decline (Brenda et al., 2009). Bringing care into this range of challenges has the potential to present further difficulties such as loss of autonomy and social isolation and for an older person to find themselves in a position of ‘ego integrity’ rather than ‘ego despair’.

Hvalvik et al. (2011) found through their small-scale phenomenological study with older people in receipt of care at home, that reaching a position of acceptance eased the passage through the transition. They claim that acceptance is attained through flexibility, recognition and hope,

from a valuing of self and from knowing and understanding their selves, their strengths and weaknesses, along with how they see their selves in the context of their past experiences. Janssen et al. (2011) carried out a qualitative study with older people receiving community care to identify sources of strength. They found that, whilst a number of participants found reaching acceptance to be empowering, it was an extremely difficult and far lengthier process than they had hoped for. Supporting Erikson's theory about the 8th stage of integrity vs. despair, the participants also looked back on their lives with a “wisdom”, and a “detached concern with life itself” (Erikson et al., 1986, p.37). They felt a sense of pride and achievement whilst at the same time acknowledging the mistakes they may have made and difficulties they had faced. They claimed that this personal integrity helped them to face the difficulties they now experience.

The participants to both these studies report that, whilst they may not be wholly content with their lives, their previous life experiences provided them with skills and strengths that helped them to manage the challenges of their new situations. In their qualitative studies with older people and in particular with those facing health related challenges, Perry et al. (2014) also found that the management of the transition into physical decline was supported by past experiences. Not only did participants reflect on how they overcame previous challenges but also on how the skills that they had employed earlier on in their lives were now re-applied to the current demands. Erikson's epigenetic and cumulative principles help to explain these findings. Attaining ego-integrity at this eighth stage is a consequence of the accumulation of skills and strategies that were used in the negotiation of earlier stages in life and the development of a “comprehensive sense of wisdom” (Erikson et al. 1986, p.55)

In spite of its many critics, including Gilligan (1982), Josselson (1987) and Thomson (2017), Erikson's work endures to this day and his eight stage model is still frequently used as a framework to understand how people at different stages in their lives manage the difficulties they face (Mauk, 2009). Some empirical studies with older people have used the model to prompt older people, and particularly those with dementia, to relate their experiences (Neumann, 2000 and Holm, Lepp and Rinsburg, 2005).

For the purposes of this research, whilst Erikson's theory may not offer up a perfect answer to my questions, it seems to provide some excellent insight and guides me to a better understanding of how self is experienced as one ages.

3.1.4 Exploring the conceptual framework

Having explored the different views of self and identity, there are different perspectives, from very different theoretical traditions. (Schwartz, Luyckx, Vignoles, 2011). It is also impossible and implausible that in a post structural world, one could find a consistent definition of self and identity (Kashima, Foddy, Platow, 2002), and Cote (2006) calls for a defragmentation of theories and a pooling of cross disciplinary studies. However, in an attempt to draw together aspects from these theories to form a framework useful for this study, it is useful to highlight the question, ‘is there a pre-determined version of self that evolves and develops and is discovered along life’s journey or is there in fact no ground plan and self is constructed along the way?’

Erikson’s Life Stage theory is based on the tenet that a person’s biography exists and must be discovered and unfolded as it moves through the eight stages of psychosocial development. The symbolic interactionist view is that the transient self changes and reconstructs itself to fit into the social context. Stryker’s interpretation is one that focuses on individual agency, as demonstrated through his notion of ‘salience hierarchy’. The level of importance a person attaches to a particular identity will determine how much energy they give to that role and how successful they are in that role. It is this agency that I believe bridges the two theories. Swartz et al. (2011) suggest that the two are not mutually exclusive and that whilst we may have a self from the beginning that very self chooses to construct itself within selected social situations. For example, I have a caring nature and I have chosen in the past to invest heavily in caring roles that call upon this aspect of my character. Whilst I may have been predestined be caring by nature, it is the carer role that allows me the opportunity to learn more about this aspect of my character, and to sustain and develop the caring characteristics. Without that opportunity I may not actualise this aspect of myself. Swann and Bosson (2010) suggest the social context reinforces characteristics and provides stability of self. Not only do I select a context in which I can demonstrate my caring nature but in turn this environment serves to re-assert my caring self.

These two views, whilst originating from very different theoretical positions, are not necessarily dichotomous. Strengths can be taken from each and applied to the context of this study. Janssen et al. (2011), in their study with people receiving long term community care, discovered that older people gain strength not only from the individual domain, that is, their

own personality traits, but also at the interactional level with family, friends, the community, and with care professionals, and within the contextual political and societal domains.

I see how understanding role identity can help to interpret the older person's perspective. Within the home there may be familial role expectations (Stryker, 1968) that are threatened when frailty sets in and role responsibilities and actions cannot be executed. When someone is in receipt of care, they may partake in activities that are not consonant with one's role, and may be seen as embarrassing leading to feelings of low self-esteem, failure and despair. This may become even more damaging when a significant other is present for example a husband or wife as "expectations of others define roles and enter the structure of the self." (Stryker and Statham, 1985, p.324). Roles may change within an environment of care and opportunities may be seized to maintain aspect of identity that is threatened by the illness and the ageing process.

Erikson's life stage theory contributes to my understanding of how care interacts with an older person's sense of self. It contributes to an understanding of the later stages of life and to the understanding and interpretation of the participant's thoughts, feelings and behaviours and whether they are typical of this stage. Through the narrative stage of this research, I explore with participants how they have negotiated their journey through the various stages and in particular into a position where they are in receipt of care. I also explore the extent to which successful or unsuccessful negotiation of earlier stages has impacted on how well the older person manages within this environment.

3.2 How older people in receipt of care feel about getting older and receiving care

My conceptual framework is built using both Erikson's life stage theory and Stryker's role theory. Erikson proposes that each stage of life is characterised by tension and conflict that must be resolved in order to progress satisfactorily to the next stage of life. For the older person the 8th stage is a battle between integrity and despair. In later years, an older person might ask questions such as "Do I feel proud of my life?", "Do I have unresolved issues?", "Is there work still to be done to make any amends?". Only after addressing the questions will one reach a position of either accepting one's life as being satisfactory or feel disappointed and despondent that things on the whole had not gone well (Erikson et al., 1986). Erikson saw that this conflict takes place within a context of interaction between

individual and society. This interactionism is reflected by Stryker who saw that through role identity a person builds self-conceptions and attributes meaning to themselves.

Erikson suggests that any resolution of the integrity vs. despair conflict involves reflection of a life lived. Yet this reflection takes place at a time of life when typically energies are depleting and other challenges must be overcome, including those related to performing basic acts of living. The purpose of this section 3 of the literature review is to look at the physical and emotional consequences of the ageing process for an older person in receipt of care. I explore the difference between subjective age and chronological age before introducing the idea that older people may move into a period of gerotranscendence when spirituality matters become more important than those of the material world. I then look at the different strategies that older people might employ to adapt to the physical limitations that getting older can bring before finally exploring how an understanding of such issues can influence care.

3.2.1 Ageless vs. Ageful

It is a dominant view in literature that many older people do not feel their age. A discrepancy between subjective age and chronological age (Gana et al., 2004) leaves many feeling younger than they actually are. They may look older, but on the inside they feel years younger and it is only when they catch sight of themselves in the mirror do they realise they are getting old. Whilst their physical appearance may give the impression to others that they are old, their internal energies are stronger and they may still feel a zest for life that is belied by their outward appearance. Furthermore, studies find that it is subjective age and not chronological age that predicts psychological and health-related outcomes (Kotter-Grühn et al., 2009, Stephan et al., 2011). Steverink et al., (2001) claim that age identity has a positive effect on physical health, and a younger subjective age along with a positive perception of old age can contribute to improved health and well-being and even the prolonging of life.

As part of a postmodernist attempt to challenge the traditionalist view of old age as a time of decline and neglect, Featherstone and Hepworth (1989) introduced the idea of a mask of ageing where the ageing body in the mirror is not a reflection of the self that sees it. The outwards signs of physical ageing, including greying hair and wrinkles, mask the true feelings of the person underneath. There is incongruence between the outward appearance, and the subjective inner self which, in contradiction, remains young. The mask is used to “cloak socially unacceptable aspects of ageing” (Biggs, 2003, p.53) and there is a tension

between what the public see and how the older person feels inside. As the author J.B. Priestley describes when he catches sight of himself in a shop window

“It is as though, walking down Shaftesbury Avenue as a fairly young man, I was suddenly kidnapped, rushed into a theatre and made to don the grey hair, the wrinkles and the other attributes of age, then wheeled on stage. Behind the appearance of age I am the same person, with the same thoughts, as when I was younger” (cited by Featherstone and Hepworth, 1989, p.148)

Participants in the study by Rozario and Derienzis (2009) allude to the mask of ageing when describing the contrast between how they appear and how they feel: “I guess you couldn’t escape that [feeling old] by looking in the mirror” (p.547) and “I’m not old may look it, I may have the age, but I’m not old. That’s’ it! You finished” (p, 547). Hurd (2000) studied older women in a day centre setting and identified participants wanting to differentiate themselves from those they considered old. They strived hard to be seen as younger than their chronological age, and the greater the disparity, the better they felt about themselves. They see not being old, as a fight against the stereotype image of people of their chronological age. Thompson (1992) suggests that the declines and losses associated with old age result in an increased salience of the negative attributes related to age and ageing. As a consequence older adults will attempt to distance themselves from their age group and use such phrases as ‘you are as old as you feel’ and ‘feeling young inside’. As one participant in Rozario and Derienzis’ study stresses

“I don’t want to be a senior. I don’t want to be old. I want to do as I feel like, and that’s what I do. I don’t care. I may be 83, but if I want to do the twist, I’m gonna do it. And I did it last month”. (p.548)

Stryker’s role theory is evident for the Rozario and Derienzis’ participants. Their comments suggest that the role they believe society expects them to take is one consonant with decline and loss. Yet they are choosing to reject such a role and take on a more vital position in their world. One participant even fears that slipping into the role of age and decline would be followed by the end of life. These older people are choosing a role that supports their view of their selves and rejecting a role that is aligned to the view of others. This very much reflects what Erikson refers to as the ego’s “assurance of its accrued proclivity for meaning” (1963, p.268). These older people strive to remain involved and committed to life and in doing so affirm their own values. Bytheway et al. (2007) warn, however, that as time goes by the mask becomes dominant and tensions grow between inner private feelings about self and the image

that is portrayed to the public world and reconciling the inner age with the outer age becomes more difficult. Ballard et al. (2005) cautions that as the outward signs of ageing increase, expressing the younger inner self becomes even more problematic and the older person begins to act old, taking on an aged identity. Thompson refers to this as internalised oppression (1995), which can challenge the individual's capacity to prepare for the future and the end of life. Hurd's study (2000) found that older people who are aware of the precariousness of feeling younger and that resisting the physical and mental declines of old age becomes more challenging and opportunities to express vitality are reduced. As one participant expressed: "Old people just give up. My father said he's had enough and six months later he was gone. Said he's lived long enough and that was that" (p.427). Nilsson et al. (2000) describe how a decline in physical and/or mental abilities can result in a disrupted reality. They suggest a withdrawal from social interaction that is not borne out of a transcendental need for reflection, as Tornstam suggests. Instead there is a desire to be left in peace to avoid any further changes to their lives, or any taxing and unbearable, unwanted demands on their personal resources. Johnson and Barer (1997), alluding to Erikson's 8th stage of tension between integrity and despair, refer to this period of confusion as a 'discontinuity', when self may reconstitute and change in the face of later life challenges to physical and mental well-being. I have known some previously happy, peace-loving, genial older people become understandably solemn, argumentative and unfriendly when faced with the sometimes extreme physical discomfort and pain that can accompany old age.

Whilst the mask of ageing theory focuses on incongruence between outer self and the inner self, Kaufmann's theory of agelessness focuses on continuity and claims that there is nothing fundamentally different about being older. The identity of younger years simply continues into old age, and who we are as an older person is the same as who we were as a younger person. In her study with 60 people aged between 60 and 97 years, Kaufmann (1994) explored the concept of the ageless self, concluding that, in spite of their rising chronological age and the changes in their physical and social functioning, older people experience a continuity of self. She claims that they

"Do not speak of being old as meaningful in itself. [Rather] they express a sense of self that is ageless - an identity that maintains continuity despite the physical and social changes that come with old age" (p.7).

In this way older people do not see old age as a distinct period in life but rather they emphasise the continuity of the ageless self. They see themselves as they had been

throughout their lives. Moreover, Kaufmann suggests that the ageless self mediates the impact of change. If self is constant then the impact of change will be reduced. Rozario and Derienzis (2009) report some participants referring to agelessness and a continuity of self. Expressions such as “I just feel like I am the same person” (p.546) and “I was born this way” (p.546) suggest that these respondents see their current selves as being a continuation of their younger identity and that there is nothing fundamentally different in being older. However, I suggest that when physical functioning means that one has to be cared for at home, the changes to lifestyle are fundamental. Moving into residential care results in older people being amongst strangers and takes them away from the way of life with all its habits and routines, that nourished their sense of self (Barer, 1995). Even those who remain in their own homes may no longer be able to visit family and friends and social connections may be lost. Roles are renegotiated, and old ones may be abandoned. An older person who was once an active and participative member of the family and of society may lose some of the previously held roles and take on the role of cared-for. It was those salient roles that enabled the development and maintenance of identities. However, Erikson suggests that the behaviours, traditions, and beliefs that have persisted through life, along with the coping strategies that were employed at earlier stages help to overcome such challenges (Erikson and Erikson, 1998). Even when an older person experiences extreme changes in external circumstances, internal continuity may remain and this internal continuity increases the probability that the individual will also perceive his or her life as having integrity (Lieberman & Tobin, 1983).

A criticism of the theory of agelessness comes from Andrews (1999). She suggests that Kaufmann’s gerontological view of agelessness strips the older person of their history, erasing their years of experience in “depriving them of one of their most hard-earned resources: their age” (p.301). She asserts that agelessness promotes ageism. Whilst we celebrate difference across domains of race, gender, religion and nationality we should also value the experience that age brings and that “years are not empty containers; important things happen in that time, they are the stuff of which people’s lives are made” (p.309). She observed that older people’s identities are both “durable and dynamic” (p.313) and that “old age can be a growing into ourselves. We are still the same people who always have been, but we are more deeply so” (p.311). She stresses that old age is no different from any other stage and old people are old and gerontologists, and older people themselves, should accept that they are. She goes on to argue that in advocating agelessness, theorists fail to acknowledge the uniqueness of old age. Furthermore, they also discriminate against those older people that

are unable to maintain the business (Ekerdt, 1986) of earlier years and to fight the normal ageing of the body. Nilsson et al. (2000) suggest that as emotional and psychological energies are depleted by the demands of coping with daily living, an older person may feel old. Andrews' anti-ageless, ageful approach offers some relief from trying to remain young and busy in order to be seen as successfully old. Gibson (2000) goes on to state that it is only through acceptance of the ageing self that one can navigate through the sometimes "hazardous journey" (p.778) of old age. He urges older people to accept the ageing process and the changes that it brings, including those to their physical appearance.

3.2.2 Spiritual reflections on ageing

Andrews' position is one that focuses on a spiritual acceptance of the wisdom and maturity that old age can deliver whilst Kaufmann's agelessness is a "potent societal script in 'successful' aging" (McHugh, 2000, p.103). Johnson (2009) sees that growing old can take on a contemplative spiritual dimension that can mean a disengagement from the physical and social activities that mark someone as agelessly and successfully negotiating old age (Johnson, 2009). Faced with greater health and functioning challenges they focus more on the subjective aspects of their lives and less on the objective physical indicators. Tornstam's psychosocial humanistic theory of gerotranscendence (1996) describes how the individual at this stage focuses more on achieving wisdom and maturation and rejects materialism for transcendentalism. This is a period of spirituality when the individual may become more selective in his/her choice of, or perhaps even withdrawing from, social and other activities, indicating a greater need for reflection. Whilst at first sight gerotranscendence may seem to resemble Cumming and Henry's theory of disengagement (1961), gerotranscendence represents not an escape from the mainstream of life but rather a move towards a new perspective and to new experiences (Dalby, 2006). Jung (1959) suggested that a natural part of growing old entails an increase in introspection and the pursuit of more spiritual goals. Carstensen et al. (1999) propose that as the end of life draws closer, the older person will divert resources away from future investment goals, focusing more on emotion-orientated and present-orientated goals. However, Dalby (2006) warns that spiritual pursuit may be a result of cultural influences and that gerotranscendence may not be as evident in some societies. She concedes though that a highly complex relationship between culture, age, religious beliefs, and personal history can determine whether an older person develops Tornstam's transcendence

Joan Erikson (Erikson and Erikson 1998) extended her husband's 8 stages to a 9th gerotranscendent stage, when one typically redefines one's perception of life and death, develops a reduced fear of death, loses interest in needless social interaction and has a diminished interest in material things. At this time the frail older person becomes more aware of their vulnerability due to mental and physical decline and they begin to mistrust their ability to maintain their autonomy and independence. Lack of energy affects personal energies, leading to feelings of incompetence and inferiority. She described this stage as a time of mistrust vs. trust. She placed the dystonic element first "in order to underscore its prominence and potency" (Erikson, 1998, p.196) thus highlighting the difficulties faced by older people at this stage of their lives. Yet if one is able to fall back on the trust one has developed through life, it is possible to reach acceptance of the dystonic aspects and continue to grow and to gain more wisdom (Erikson & Erikson, 1997). If one can trust that they are one and the same person, in spite of the life changes that come with being old and frail, then it is possible to reach an acceptance and adjustment to the realities of life.

My discussion thus far supports the Eriksonian life stage theory yet also acknowledges role theory, in that self is realised as identity through salient roles. It is through interaction with others that identity is constructed. Yet Erikson (1998) suggests that in the ninth stage an older person may struggle, because of incapacity, to relate to and interact with others. The theory of gerotranscendence proposes that this isolation may be more desirable as the older person places less importance on superficial relationships and focuses more on deep and close relationships. This period of transcendence brings a need for reflection, introspection and meditation. Tornstam (2003), in further developing his theory, carried out a Swedish postal survey of 1,215 people in the age range 74–100 years. He found that the majority of participants were more selective in whom they chose to spend time with and wanted more time for contemplative solitude. He suggests that in this way transcendent older people recognise the difference between their self and their identities through the roles they had enacted in life. Thus, in wanting to get close to their genuine selves, they abandon many roles.

3.2.3 Loneliness and isolation

Whilst some older people experiencing gerotranscendence may choose their own company over that of others, literature reports that many older people experience feelings of loneliness and isolation. Whilst the terms loneliness and isolation are often and erroneously used interchangeably (Victor et al., 2000), authors suggest that they refer to very different experiences. Loneliness refers to a feeling when someone has a sense of lacking closeness and social interaction with others and is a very personal and subjective state (Age UK, 2016). De Jong Gierveld et al. (2016) suggest that feelings of emotional loneliness arise when not only the number of existing relationships is fewer than what one considers desirable but also when the quality of those relationship means that intimacy has not been realised and feelings of belongingness are replaced by emptiness and rejection ensue. Weiss (1974) suggests that feelings of emotional loneliness are experienced particularly when there is absence of a close relationship of understanding and care.

On the other hand, social isolation arises when there is a lack of contact with family or friends, an absence of community involvement, or limited access to services (Victor, 2012). Weiss refers to social isolation as social loneliness and something that can be alleviated by the presence of friends and peers rather than for example by spouses and romantic partners. However, it is possible that solitude can be enjoyed by people and can lead to creativity and self-realization, and is an approach for developing one's own individual space. Tiwari (2013) posits that being alone can be seen as an essential component for spirituality and self growth, unlike loneliness that brings feelings of emptiness and separateness.

Hence, it is possible to be socially isolated and alone and not experience feelings of loneliness, and equally it is possible to be in the company of others and still feel lonely (Age UK, 2014). Age UK, in their evidence review of loneliness in later life (2014), report that 6 to 13 per cent of older people claim that they are often or always lonely and Wave 5 of the English Longitudinal Survey of Ageing (Banks et al., 2012) report that 8 per cent said they often felt lonely.

There are many factors that may cause older people to experience feelings of loneliness. Age UK (2014) evidence that older people living on their own are more likely to say they feel lonely, whilst Beaumont (2013) reports that gender is a contributory factor with women being more likely to say they feel lonely than men. Where people live can also be a factor. Bolton et al. (2012) suggest that living in a rural area can contribute to feelings of loneliness,

yet Age UK (2014) suggest that loneliness is more prevalent in urban areas, but acknowledge that further research needs to be carried out. Significantly for this research however, several studies suggest that levels of health and disability contribute to feelings of loneliness, with reduced mobility, cognitive impairment, and sensory impairment making a significant contribution (Beaumont, 2013, Bolton et al., 2012, O'Luanaigh, C. et al., 2012).

Loneliness is a risk factor for a number of health issues including depression, sleep dysfunction, cognitive decline and even mortality and can hasten physiological decline (Hawkley and Cacioppo, 2007, Wilson et al., 2007, Brummett et al., 2001, Cacioppo et al., 2002). Greenfield and Russell (2011) even suggest that loneliness can be as big a health risk as smoking and obesity. Holt-Lunstad et al. (2010) posit that those people who have stronger social relationships have a fifty per cent increase in chances of survival and Wilson et al. (2007) report that the risk of developing Alzheimer's disease more than doubled for those older people who were lonely.

Particularly relevant to this study are the findings of the EHRC report (2011) that reveal pervasive feelings of loneliness and social isolation for those people receiving domiciliary care. Older people reported that they had limited opportunities to leave their own homes, and very few care packages supported activities outside of the home, leaving older people feeling cut off from the outside world and lacking human company. For many this was due to their limited physical capabilities and lack of mobility, and they reported having given up on their hobbies such as shopping, going to the theatre, gardening, and attending sporting venues. However, as I explore later in this chapter, Wadensten et al. (2003) warn of the dangers of the influence of activity theory when caring for older people at home, noting that some older people in a stage of gerotranscendence may prefer to be alone and do not experience feelings of loneliness or worry about social isolation.

3.2.4 Adapting to ageing

Whilst I have explored the psychological aspects of ageing from the individual perspective, it is also important to explore the practical steps that older people take when they are faced with the challenges of old age. Research indicates that older people place importance on trying new activities (Reichstadt et al., 2010) thus creating a balance between stability and continuity of self and the experimentation and growth of adaptation. Lifespan theorists see development as a lifelong process of flexible and individual adaptation to change (Baltes,

Lindenberger, & Staudinger, 1998). Baltes and Baltes (1990) recognised that people do adapt to the challenges of ageing and proposed that this can be attributed to the maximization of gains and the minimization of losses, and that this is achieved through three fundamental strategies, namely selection, optimisation and compensation.

Together these three processes orchestrate to provide a behavioural mechanism for regulating ageing and development, and in spite of the restrictions of reduced energy and function, allow people to engage in those life tasks that are important to them (Bengtson, Putney and Johnson, 2005). Selection refers to defining and committing to personal goals that support personal needs, preferences, demands and resources. As resources decline, it is important that the older person expends energy on the most important goals, making adaptive changes where necessary or replacing goals that can no longer be met. For example, it may be that an older person selects a goal of walking to the bottom of the garden once a day as they feel this is within their current physical abilities. However, in order to meet the goals, there may be a need to optimise resources, through applying or refining existing ones or acquiring new ones, and each goal may have call upon a different resource. In this example, perhaps as physical resources weaken the goal is optimised to walking out of the back door to the patio rather than to the end of the garden. Research indicates that this level of optimisation can have a positive effect, with older people who engage in optimization processes experiencing higher levels of satisfaction with aging (Freund and Baltes, 1998). When the resources at your disposal are no longer able to meet the selected goals then compensation must be made by finding alternative routes to counteract loss or reduction of capacities. Once again in this example it may be that the goal remains the same, to walk to the patio but as physical resources decline even further, perhaps compensation can be made by using a walking frame to reach that goal.

In their observational studies with older women in a day care setting, Hurd (2000) witnessed participants finding ways to confront and negotiate their disabilities, for example by reducing the number of classes they attend or by adjusting the types of activities. Likewise, Li et al. (2001) report older people employing selection, compensation and optimisation techniques, focusing more on maintaining balance rather than exercising memory skills in a physical challenge. Gignac et al. (2002) also witness older people with chronic illness using supportive devices in a compensatory way and optimising their activities to avoid pain.

However, studies indicate that whilst the optimisation and compensation processes may contribute to greater feelings of well-being (Ouwehand et al., 2006) it is these very strategies that may sadly decline as age increases (Freund and Baltes, 1999). Studies suggest that this may be due to further age-related loss of resources (Baltes and Lang, 1997, Lang et al., 2002). Findings indicate that those fortunate older people who are rich in resources, do continue using optimisation and compensation strategies. Gerotranscendence, through focusing more on the spiritual aspects of their lives that eclipse their disabling conditions, not only transcends the negative effects that physical limitations may have on their sense of self, but also promotes feelings of wisdom and maturity. This could be viewed as a process of selection, compensation and optimisation, where goals are reassessed, and resources that support contemplation are employed, compensating for the losses of old age.

3.2.5 Implications for care

Understanding an older person's experience of ageing and self within the cared for dynamic has the potential to support fruitful caring relationships. Any social care assessment and intervention should consider whether an older person feels a sense of integrity or despair, what their subjective ageing experience is, and how they adapt to their change in circumstances. The carer may be one of the very few people the older person comes into contact with and has the potential to help resolve the integrity vs. despair issues that are being faced. They may be able to support the older person in answering the questions that may still be left unanswered such as the ones mentioned earlier: "Do I feel proud of my life?", "Do I have unresolved issues?", "Is there work still to be done to make any amends?"

Furthermore, a carer may gain some insight into how the older person feels about getting older. Take for example Mary, the 94 year old lady I introduced earlier. When I first met her I didn't see her inner person and saw her only through the mask of an old lady with several physical limitations. However, as time moved I saw beneath the mask and became more receptive to the expressions of her inner self and I encouraged her to laugh and joke and to be playful. I recall however, when I took a photograph of her using my phone, she looked at it and expressed horror. She could not believe she looked as old as she did. In spite of my reassurances it was one of the few times I saw her feel and express sadness and disappointment as she felt so much younger than the photograph revealed to her. Nevertheless it became a very happy and positive relationship. However, she recounted how many carers did not take the opportunity or even have the desire to get to know her. They saw

her through the mask, as just a frail old lady and struggled to recognise and engage with her lighter side.

A carer may also be able to recognise signs of the 9th stage of gerotranscendence. Understanding that the older person is at this spiritual and reflective stage in their lives has the potential to enhance the quality of care (Wadensten and Carlsson, 2003). Perhaps there may be opportunities to encourage and support reflection, thus helping the older person to reach transcendence. Wadensten and Carlsson (2003) observe, however, that there is a paucity of research into the practical measures that can be taken by care staff once they recognise the signs of gerotranscendence. They suggest that care staff should firstly reach an understanding through awareness and knowledge of the process of gerotranscendence and propose that carers should try to recognise the signs and behaviours typical of this stage. They suggest that an older person may display an alternative definition of time, living simultaneously in the past and the present. They may form closer relationships with younger people, have a decreased fear of death, and, recognising that an explanation of everything is not possible, may prefer supernatural explanations. They may also take greater pleasure in the smaller things in life, developing a decreased interest in material things. They may recognise aspects of their selves they had not noticed in earlier years, become less egotistical and self-centred and caring less about bodily signs of ageing. They might spend considerable time reflecting on their childhood, and reflect back on their lives with a new understanding and insight. Another sign of gerotranscendence is a move away from having many social contacts, preferring deeper more meaningful relationships, even avoiding social activities preferring to be alone to reflect.

However, Wadensten et al. suggest that care staff may be influenced by activity theory in that life satisfaction of older people is measured by the extent to which they maintain their social roles and remain socially active. Hence, the carer who believes the older person's life to be passive and dejected may see a cure through activating the older person (Wadensten and Carlsson, 2003). Withdrawal and introspection should not be regarded as a sign of unhappiness that must be remedied by forced activity and social contact. Wadensten et al. go on to recommend that carers should accept the components of signs of gerotranscendence as normal signs of aging and in working with older people carers should demonstrate a reduced preoccupation with the body. They should accommodate alternative definitions of time, allow death to come up in thoughts and conversations, facilitate and encourage personal growth and

encourage and facilitate positive solitude. They should discuss the older person's experience of ageing and facilitate reminiscence and storytelling of previous life experiences.

In this review so far I discuss how the battle between the 8th stage of integrity and despair takes place at a time when old age presents many challenges including performing acts of daily living. I also discuss how some older people, particularly those being cared for at home, struggle to maintain the agelessness that others may aspire to and how they strive to adapt to the challenges of ageing through the maximization of gains and the minimization of losses using selection, optimisation and compensation techniques. Yet at the same time they may retreat from unnecessary social engagement and enter a stage of reflection in order to manage the challenges of the 9th stage of mistrust vs. trust. I go on to propose that domiciliary care can support the older person to reach a position of integrity and go on to trust their resources to take them through the final stage of life.

However, there are other factors that influence how successfully the older person navigates this time of life and I now look to how societal and political forces can support or impede this process.

3.3 External influences on the experience of self

I will now explore how gerontological theories have evolved and how they view the way in which society supports older people and the extent to which older people are considered a burden to society or as a group that have the potential to make a positive contribution. I then examine how societal and cultural ageism has the potential to impact not only on the design and delivery of care agency practices and procedures but also on the carers' ways of working.

3.3.1 Sociological Perspectives on ageing

Theoretical understandings of ageing have taken many guises over recent years. The end of the Second World War saw a palpable change in society as demographics shifted. With a shortage of younger people and a growing older population, the post-war political and economic environment began to see ageing as a problem for society (Jones, 1983). Social gerontologists sought to interpret the effects of these changes and to understand their social, health and economic policy implications. The functionalist view of society likened society to that of a complex and living, growing organism in which 'organs' or institutions interconnect and function to sustain the whole. If a society is to maintain equilibrium these parts must

work together (Giddens, 1993). Talcott Parsons, the most important figure in the structural functionalist school of sociological thought (Treviño, 2001) proposed that people, driven by their values, do want to cooperate and to create social integration. As Knapp suggest:

“people act on the basis of their values; their actions are oriented and constrained by the values and norms of people around them and these norms and values are the basis of social order” (1994, pp. 191-192).

However, as societies evolve and become more complex so do the roles that people play within them and so, at some point, not every member of that society has the skills or abilities to perform those roles. Moreover, in the face of great change, disequilibrium ensues and at this point part of society must make adaptive changes.

One variant of functionalism, disengagement theory, attributed to Cummings and Henry (Cummings and Henry, 1961, cited on Powell 2001) states that older people go through a natural and inevitable process of disengaging from work and social roles in preparation for their ultimate disengagement, death. Drawing on the functionalist approach, a positive consequence for society of this gradual disengagement is that when they do finally withdraw, their absence is not felt too harshly by society and it will continue to function without them and furthermore, such withdrawal also makes space for younger workers (Neugarten, 1996). Of course, through disengagement, the older person is passing knowledge and power to the young in society thus ensuring that the younger population have jobs and roles into which they can develop and grow. Consequently, families and organisations encourage disengagement based on the degree to which the older person is able to fulfil their roles. Whilst complete disengagement occurs when both the organisation and the individual agrees it is appropriate, disjuncture occurs when either side resists or crisis may ensue. A good illustration of disengagement process is retirement, with its opportunities for relinquishing of employment responsibilities and the pursuit of goals that are compatible with the disengaged state.

Whilst in the 1960's the theory of disengagement was seen as revolutionary, it has been heavily criticised. Hochschild (1976) found that Cumming and Henry's data, collected by way of survey and questionnaire methods, evidenced a significant number of older people not disengaging from society. Yet Hochschild argues that Cummings and Henry classified these non-disengagers as being unsuccessful adaptors to old age. He goes on to state that this made the theory impossible to empirically refute. Furthermore, he reasons that the term disengaged

is unclear and “what is missing is evidence about the *meaning* of the daily acts that constitute engagement or disengagement” (p. 66). Additionally, ‘older’ is an umbrella term that ignores the diverse and complex processes involved in growing older. Social withdrawal in older age is not culturally universal. Powell (2001) goes further by stating that disengagement theory provided Governments with justification to legitimately create age-defined boundaries removing people from the workforce.

Havighurst (1961) believed that disengagement theory was ageist. His activity theory places great importance on older people being dynamic and active participants in society and that this activity is a determinant of feelings of physical and emotional well-being. The measurement of successful ageing is through the extent to which the older person continues to engage in the social context, and to maintain social roles and relationships. How happy someone feels is in direct proportion to how active they remain. Furthermore, as ageing brings losses in terms of those roles and activities that can be pursued, these must be replaced by others thus keeping the ageing process at bay (Havighurst, 1961).

However, some argue that activity theory is idealistic and optimistic (Bengtson and Settersten, 2016). Access to social opportunities and activities are not available to everyone and even if they are, the older person may not want or even be psychically able to take part. Not all people young or old find fulfilment in the presence of others, or in the participation in activities, and not all older people want to be active. They may enjoy the idleness that older age can bring.

Estes (1979) argues that disengagement and activity theories failed to explore how social structures affect the ageing process as “[the] focus [was] on what people do rather than the social conditions and policies that cause them to act as they do” (p.11). Several forces came together in the 1970’s that meant that gerontologists began to focus more on the issues of power and inequality in society. The rise in oil prices, the fall in economic growth and the increase in unemployment and inflation resulted in an economic crisis and public expenditure cuts, particularly in relation to welfare funding. Political and ideological changes ensued. As the demographics changed and older people outnumbered younger people, the strain on the public purse began to feel intolerable and a biological reductionism followed, where “older people came to be viewed as a burden on western economies, with demographic change seen as creating intolerable pressures on public expenditure” (Phillipson, 1998, p. 17).

The political economy theory of ageing argues that there are political, societal and economic forces that determine how someone experiences older age. With Marxist theory of class structures at its foundation, the theory postulates that it is not chronological age that determines whether someone is economically dependent. It is the relationship between the individual and the market forces at play and how those forces impact on pension policies, retirement age and the welfare state (Walker, 1981). Townsend (1981) arguing from a social constructionist position, posits that actions of the state and of society create a dependency in the older population and

“..the evolution of the economy, the state and social inequality has been taken for granted, and the implications of the trends for people as they become older neglected.”(p. 6).

The 1970's saw a dramatic fall in the number of people aged 65 and over in the workplace. The Government espoused that this great achievement gave older people the well-deserved rest they had earned, alluding to the fact that retirement was synonymous with decline. Yet this rest was not always welcome and “Many who have retired deeply regret their inactivity or loss of status” (Townsend, 1981, p. 10). Pensioners also suffered a dramatic loss of income with inadequate state provision through the pension system. Walker (1981) assesses the loss of income to be up to one half, and that this lack of resources prevents participation in society.

3.3.2 Care in a postmodern world

Political economy of ageing has been criticised for its focus on economic determinism and for emphasising structural constraints over individual agency (Higgs and Jones, 2009). Its critics argue that it operates on the premise that conflicts exist between older people and political and economic institutions. Furthermore, older people are passive reactors, victims of capitalism, oppressed by greater forces, exercising no personal agency. Wilson (1997) goes on to suggest that the political economy perspective consigns individuals to socially constructed categories and anonymises and objectifies older people. Offering a strong contrast to the political economy theory, post-modernism supports increased individual agency, with older people taking greater responsibility for their welfare. With the growth in globalisation, individualisation, and with the de-standardisation of the life course, individual responsibility for welfare takes precedence over the welfare state. Post-modernism sees old age not as period of decline but rather as time of potential that can be realised through a

mature imagination (Biggs, 2003) that can create new lifestyles for later years (Gilleard and Higgs, 2005). In the post-modernist climate, age boundaries are becoming increasingly blurred. Biggs et al. (2006) suggest that Governments understate old age poverty and that these factors erode any association between old age and poverty. However, the authors also warn that this theory takes no account of cumulative advantage/disadvantage, and cumulative inequality. The theory of cumulative advantage and disadvantage claims that older people bring with them the advantages or disadvantages that they have accumulated over a life time. Applying this concept to ageing, Crystal and Shea (1990) propose that health, education and economic factors contribute to cohort inequality that is magnified over the life-course. They posit that

“[T]hose who are initially advantaged [...] are more likely to receive a good education, leading to good jobs, leading to better health and better pension coverage, leading to higher savings and better post-retirement benefit income” (p. 437).

Furthermore, not only do earlier disadvantages affect financial outcomes in later life, but Wadsworth takes a “life-time view of the natural history of some common serious illnesses which usually begin in middle or later life” (1997, p.860). He stresses that health and access to health resources in younger years contribute to health and well-being in later years. Ferraro and Shippee (2009) introduced the term cumulative inequity.

“Cumulative inequality theory specifies that social systems generate inequality, which is manifested over the life course via demographic and developmental processes, and that personal trajectories are shaped by the accumulation of risk, available resources, perceived trajectories, and human agency” (p.1).

The focus is on how social forces generate inequality and how life-course disadvantages increase exposure to risk whilst advantage increases opportunities.

Aronson also warns that the promotion of self-sufficiency, independence, citizenship and the decline in state intervention creates marginalisation and isolation (Aronson, 2001). Social isolation is defined as a “process of becoming detached from the organisations and communities of which society is composed and from the rights and obligations that they embody” (1995, p.243). Speaking specifically about home care, Aronson (2001) argues that with underfunding and more stringent eligibility criteria, older people receiving care at home become detached and excluded from their communities and lose their identities as community dwellers. Her research with home care recipients reported some participants feeling they had

lost a collective identity and felt culturally and politically isolated. Returning to the earlier discussion about roles and how they support the realisation of aspects of self, for older people receiving care at home, the opportunities to actualise aspects of self through roles often naturally decline as they spend more time at home. Yet as Aronson points out (2001), in forcing older people out of the markets and to the margins there is a move away from interdependence. The number of roles then further declines and self is threatened. On the other hand Erikson suggests that during the 9th stage, older people do retreat into a period of reflection and have no desire for superficial relationships. However, they do place great importance on the more meaningful relationships in their lives and often the carer belongs to this selected group. Aronson (2001) suggests that carers must be recognised at the organisational for the role that they play in this regard.

Taylor-Gooby (1994) argues that post-modernism fails to take into account how the economic forces of market liberalism promotes inequality. He suggests that post-modernism acts as a smokescreen, obscuring some of the prevailing disadvantages within society. Whilst the post-modernist drive is for difference, diversity and choice, living conditions for so many of the poorest members of society are exacerbated by managerialist forces such as privatisation. These forces are evident in the domiciliary care sector in the drive for Care in the Community and the introduction of a mixed economy of care. The Equality and Human Rights Commission, in its 'Close to Home' study of domiciliary care (2011), report differential treatment related to age, with discriminatory and ageist attitudes towards older people and an imbalance between money spent on older people compared to other age groups. The study's figures indicate that less money is spent on care packages for individuals over 65. Only with a 25 per cent increase in support would these differences between age groups be balanced. In 2010 The Equality Act extended the existing regulations against ageism and gave protection to older people against age discrimination in employment, education and training. In 2012 it was further extended to give new protection to ensure that older people get fair treatment when they are receiving goods and services. Yet it is hard to see evidence of such equality. Age U.K. (2013) report that the number of people aged 85, being those who are most likely to need care, increased by 30 per cent between 2005 and 2014. Yet, between 2011 and 2014, public funding for older people's social care decreased by 10 per cent. One only has to look at the eligibility criteria, set by authorities that determine the point at which care is provided, to understand why. The Age U.K. report (2014) shows that in 2014, 87.5 % of authorities no longer fund care for older people with moderate needs,

for example needing help with dressing, washing, taking medication and going to the toilet. They now only fund care for those with substantial or critical needs. The definition of critical care needs, includes there is, or will be, an inability to carry out vital personal care or domestic routines. Substantial care needs are when there is, or will be, an inability to carry out the majority of personal care or domestic routines. Moderate care needs are when there is, or will be, an inability to carry out several personal care or domestic routines. Typically, when an older person struggles to complete basic acts of daily living they are in need of care at home. Yet they often fall into the moderate needs category and are deemed ineligible for public social care provision. The fine line between vital/majority/several care activities is subjective. The Care Act of 2014, which came as a result of the Law Commission report on the legislative framework for care and the Commission on Funding of Care and Support led by Andrew Dilnot, seeks to address these issues. Whilst the Act introduces a National Minimum Eligibility Threshold with a common threshold, the Secretary of State has the power to define this threshold. The Age U.K.'s findings indicate that it will, in all likelihood be set as substantial, as defined by the Fair Access to Care Services criteria.

In conclusion, the postmodern and post-structuralist view, that can be heard and felt in a neo-liberalist society, is that older people must be respected for their diversity and autonomy and that they can exercise choice in the way they experience old age. Whilst such a view can be applauded for its promotion of diversity, individuality and independence, its practical application within the home care market needs to consider the impact of funding cuts on older people along with such principles as cumulative inequity. Furthermore, it promotes isolation and loss of collective identity for this group of people and thus has the potential to threaten the sense of self.

3.3.3 Ageism and implications for care

It is an incontrovertible view that cultural values are socially constructed. A person's genetic makeup does not determine their value system, and they are not born placing importance on youth or seeing old age as a time of decline (Hepworth, 2000). Rather it is within the context of the human relationship that a person develops understandings of longevity and what it means to be old. Relatedness and communication are at the heart of the human process and interaction is through a complex pattern of visual and verbal symbols. It is through the use of these symbols in behaviour and in language that a person comes to interpret the biological, psychological and social changes that are inherent in the ageing process (Gubrium, 1989). In

using these symbols a person develops a range of images and stereotypes, and the labelling of people into categories becomes common place.

The positive stereotyping of older people grants them such characteristics as warmth, wisdom and loyalty (Patmore, 2004, Lyons, 2009). However, in spite of the drive for equality and diversity and “the erasure of difference between adults of different ages” (Biggs et al., .p.5), it is negative perceptions that tend to dominate (North and Fiske, 2015). Images such as that used to warn that older people may be crossing the road, show a bent over couple with walking sticks. Images like this suggest that the weakened, distorted body image is a well understood representation of old age. In the media the use of symbols such as deep wrinkles, hair loss, greying hair, liver spots, bowing legs, wheel chairs, and walking frames are frequently used to represent old age (Hillier and Barrow, 2014). Biggs (1993) refers to this stereotyping as a common-sense reality in which beliefs, whilst serving to help people make sense of the world and to legitimise behaviours, also prevent them from recognising alternative realities. This affects the responses of not only the observer but also the observed and through internalising the cultural values and beliefs, older people can develop behaviours that are congruent with how they think others see them (Horton et al., 2008). Stereotyping ‘influences the self-image and behaviours of its victims’ (Falk, 2001, p.129)

Ageism is stereotyping, and despite efforts to change such conceptions, it remains embedded within society and “in the U.K. today, age discrimination is part of the fabric of our everyday lives” (Bytheway et al. 2007, p.5). The term successful ageing is, in itself, ageist (Calasanti, 2015). It promotes a naive ideal of agelessness that is measured quantifiably by level of activity, autonomy and responsibility, and by the business of people and their contribution to society (Ekerdt, 1986). Weiner et al. (2012) refer to the term as an oxymoron and that ageing well denies the normal ageing of the body, creating a Cartesian split between mind and body. Biggs et al (2006) propose that to claim that there are no differences between ages in terms of desire for social engagement and self-development is simply to move the agendas from one generation to another. Such a claim ignores what is happening at different stages of life, and how the goals, aspirations and physical realities for the older cohort may set them apart from their younger counterparts

It seems inevitable, against a backdrop of stereotyping and the consequential ageism that pervades into Western culture, that there is potential for ageism to be evident at the point of care (Crawford and Walker, 2006). Billings (2006) explored staff’s experiences of ageist

practice in the clinical setting, including those working in the community, and identified discriminatory and patronising practices. The Equality and Human Rights Commission report home care services that are rife with ageist practice (Equality and Human Rights Commission, 2011), citing examples of denigrating behaviour such as shouting loudly, talking very slowly at older people as if they were unable to understand, talking over their head to another care worker, using a mobile phone during care and even expressing disgust at incontinence. The report expresses concern that carers are taking an ageist stereotyping stance, reducing older people to a single identity based purely on their age.

Green (1993) saw the identity of an older person as being determined by what is done to them or done for them, rather than for what they are able to do themselves. He cites such terms in practice as “for the aged”, “to the aged” (p.96). In this way care practices construct and reinforce the stereotypical ageist identities of older people, creating a fictional unity (Bruner, 1996). In their qualitative study that examines meanings and experiences of ageism for older people, Minichiello Browne and Kendig (2000) quote one participant as saying “I always thought that we were old and we had to just take what we were given and there wasn’t much we could do about it” (p.273). In their ageing study with older people, Hoban Beresford and Fleming (2013) found that traditional ways of working take a ‘doing to’ approach that fails to work with and alongside older people, involving them in decisions about the shape of their care. In this way, the authors write, older people are seen as a homogenous group that are encouraged to be passive and dependent through disempowering, task centred practice. Diamond (1992) goes on to state that older people may develop a patienthood persona, and suggests that time constraints of care packages mean that paying attention to emotional need is sacrificed in the fight to meet the deadlines of daily assigned tasks. Hockey and James (1993) also describe a move away from personhood, through care that promotes dependency and uses infantilising practices. Townsend (2007) goes on to claim that care services create a structured dependency and that conditions exist where older people are provided with a package of care that fails to encourage self-help.

Tanner and Harris (2008) suggest that some older people do all they can to resist being seen as dependent for fear of losing even more autonomy. Seale (1996) reports some people actually refusing support for the same fears. Hurd (2000) finds, in her observational study, older people working hard to shatter the pre-conceived ideas that younger people have about their capabilities. Battling against their chronological age is, according to Thompson (1992

art 4), an older person's way of preserving dignity and resisting the negative images of old age. Atchley (1991), on the other hand, claims that most older people are not affected by the negative stereotyping around old age and do not let it affect them. However, the participants in Nilsson Sarvimäki and Ekman's study (2000) express a despondency and resignation to the fact that they are seen as old by society and there is little point in wasting energy fighting the stereotyping behaviours surrounding them. Whilst Tanner and Harris suggest that some older people might resist aligning themselves to the negative images, others may acquiesce and accept the situation by "not making waves" (p.16). They warn that, either way, these behaviours are a reaction to ageism.

With regard to practice around delivering older people's domiciliary care services, Olaison (2010) examined social work case files. She looked at how needs are documented, to what extent older people's wishes and requirements are considered, and whether social as well as medical and physical needs are taken into account when formulating the support package. She found that there was little room in a standardised assessment process for including the older person's narrative, and that the needs based assessment serves to categorise older people to fit into organisational and legislative frameworks. The Single Assessment Process (SAP) was introduced in the National Service Framework for Older People in 2001. It was to ensure that social care and NHS services deliver person-centred, holistic care that treats older people as individuals, enabling them to make their own choices about the care they receive. However, implementation of SAP has been slow and evidence suggests that the assessment forms are needs based, do not allow for a truly holistic assessment, and that the system is failing to involve older people as active partners in assessment and planning of services (Parker and Bradley, 2010). In their independent enquiry supporting the Equality and Human Rights Commission study, Sykes and Groom (2011) interviewed 40 older people receiving care in England, and found that many of the participants felt that the assessment process had merely happened to them and that they had very little choice about the outcome,

“..the process seemed thorough, they did not feel there was much opportunity for the care recipient to say what they wanted: 'they' arrange everything, and tell you what 'they' are going to do” (p, 36,) (author's emphasis).

Hughes (1995) set out a range of values to be adopted by anyone involved in the care of older people. Each person should be valued for their personhood, their citizenship and their lives should be cause for celebration. In other words, an older person has equal value to any other

and should be afforded the same rights as any other citizen and they should be applauded for their achievements and diversities. In order to fight ageism, she goes on to frame these values with a set of principles that should be inherent in social care practice and should be used to evaluate the effectiveness of interventions. They include empowerment, participation, choice, integration and normalisation. Not only should practices promote autonomy, but they should encourage older people to participate in decision making processes and feel able to make their own choices about care. Furthermore, social inclusion and engagement in activities should be part of normal practice and social care workers should do all they can to ensure that they provide older people with the resources they need to live their lives as they wish. Hoban Beresford and Fleming (2013), following their collaborative study with older people, call upon social care providers to identify older people not in terms of need but rather as a rich and diverse societal resource. They recommend that older people should be able to decide for themselves the kind of care that enhances their own sense of well-being, and to shape the services accordingly.

In conclusion then, age is a socially constructed phenomenon and older people are seen by many as a homogeneous group, and old age is often depicted, through the use of symbols, as a period of decline not strength. In spite of the post-modernist drive for equality, diversity, individuality, it is negative perceptions that tend to dominate. Furthermore, care assessment and care delivery practices have the potential to treat the older person in need of care as a passive recipient, unwilling or unable, because of age, to make decisions about their care. There is also evidence that ageism in care practice is commonplace, reducing older people to a single identity based purely on their age. Yet for many older people who are often socially isolated, care relationships can play a fundamental role in supporting their struggle for ego integrity and the move into a position of trusting themselves and their environments in the final stage of life.

3.4 Domiciliary care, self and ageing –current practices

Returning to the current landscape of care that I introduce in chapter 2, I now examine research evidence of ways in which care helps the older person negotiate the integrity vs. despair and mistrust vs. trust stages. Having established that self is realised through identity with others, I look to see the kinds of roles that are evident within the care dynamic and how these support the older person. Firstly I look at how individuality is respected within domiciliary care, how this impacts on feelings of isolation and how carers' attitudes can

directly impact an older person's sense of self. Secondly, loss of autonomy has been identified as a significant factor and as an older person loses control of their home and their body space they can potentially lose their personal dignity and their sense of self. Thirdly, management practices including the model of care delivery, the regularity of carers and the timing of calls are also contributory factors within the care setting.

3.4.1 Respecting individuality

Launched in 2001, the National Service Framework (NSF): Older People (Department of Health, 2001) set out to ensure that older people receive person-centred care that recognises and respects individual needs and differences. The NSF standard 2 included the recommendation for procedures that “identify and, where possible, meet any particular needs and preferences relating to gender, personal appearance, communication, diet, race or culture, together with religious and spiritual beliefs” (Department of Health, 2001, p.25). However, in 2011 the Equality and Human Rights Commission (2011) undertook an extensive inquiry into home care services and found practices that treat older people as a homogenous group showing little respect for their individual and diverse needs. The inquiry reports one size fits all practices that show little regard for individuality and diversity, including sexual orientation, cultural heritage and spiritual and religious needs. In their independent enquiry supporting the Equality and Human Rights Commission study, Sykes and Groom (2011) interviewed 40 older people receiving care in England and report accounts such as “...you were just as a number” (p 19) and “I was diminished, I wasn’t me anymore, a pudding not quite a human being” (p.15). This suggests that older people do not wish to be identified through their vulnerability and lack of ability to meet their own care needs, but rather to be recognised as individuals who have a unique identity and life history. Research suggests that staff attitudes have a key role to play in this regard (Francis and Netten, 2004), and the quality of interpersonal interactions with carers was an issue discussed across much of literature. Gallagher et al. (2008) report behaviours that are patronizing and show intolerance, impatience and lack of respect. In their small-scale qualitative study with service users and professionals, Francis and Netten (2004) explored experiences of home care to ascertain which aspects of quality are important to older people. The most commonly cited factor was the attitude of care staff, including respect, friendliness, cheerfulness and understanding. The Equality and Human Rights Commission report also highlights instances of patronising behaviour such as shouting loudly or talking very slowly at older people as if they were

unable to understand. It also expresses concern that carers are taking an ageist stereotyping stance, and that this attitude to older people reduces them to a single identity based purely on their age. Grenier and Gubermann also identify practices that promote identity exclusion through the “dismissal or diminishment of the distinctive and multiple identities of the person or group through reduction to one identity such as age” (2009, p.118), alluding to my earlier discussion in this review.

Sykes and Groom (2011) report that whilst some care workers were praised by respondents, there were also many examples of disrespectful treatment, including ignoring the older person by talking over their head to another care worker, using a mobile phone during care, expressing disgust at incontinence, and showing little regard for the home environment. Nicholas and Qureshi (2004) opine, however, that there may be some individual variation in terms of what older people need at this point of interaction. Some old people may not want or need conversation but place a greater importance on the completion of tasks whilst others see the relationship as an opportunity for friendship. The traditional task-centred model of care delivery may suit some individuals who require care that focuses purely on physical functional ability.

The attitude of care staff has also been at the centre of discussion regarding respect for an older person’s dignity. In 2006, the Department of Health carried out an on-line survey to hear directly from the public about their own experiences of being treated with dignity in care. Receiving 400 responses from both members of the public and professional health and social care staff, they identified specific examples of poor care. For example, giving an older person food whilst they were sitting on their commode, being left in soiled clothing and mocking disabilities. Gallagher et al. (2008) analysed the findings of this report in an effort to clarify the meaning and implications of being treated with dignity. They stress the importance of personalised care where older people are not treated as a homogenous group, and that individualised care will afford them opportunity to be dressed and groomed as they wish and to be addressed in the way that they consider appropriate. The DOH presented the findings of the 2006 report to care professionals as evidence of the failings of the system and in an attempt to identify where improvements could be made. Yet, in spite of the DOH findings, five years further down the road, the Equality and Human Rights Commission report (2011) provides examples of care that shows intolerance, impatience and a lack of respect. The report tells of how carers failed to help a lady with eating and drinking because they were late for

their next visit, knowing full well she was physically incapable of feeding herself. It also reports how carers placed food in front of a deaf/blind older person without telling him it was there, resulting in him going hungry and the food being wasted. Sykes and Groom (2011) also report that, whilst some respondents praised the professionalism of some workers, others reported instances of incompetence. They cite one carer reportedly microwaving all food for 10 minutes without looking at the individual cooking instructions. When challenged he responded “This’ll do”. Yet in spite of these reports and subsequent recommendations, the problems persist. Through the summer of 2012 the Care Quality Commission carried out an inspection of 250 home care agencies providing care to over 260,000 people (2013), and reported that whilst many providers were delivering a very good service, with 74% of services meeting their 5 essential standards, there were nevertheless inadequacies in care that had a severe impact on people.

Dignity is also at the heart of the United Kingdom Home Care Association resource guide (2006), with social inclusion being a key domain. The guide states that older people should not be discriminated against because of their age or their physical disability, and should be enabled to feel part of their community by taking part in social activities, and being part of their network of family and friends. Art 8: ECHR includes the right to engage in social activities with others. However, the evidence is not supportive. Sykes and Groom (2011) report older people believing it is just not possible for the carers to take them out into the community because of health and safety issues, or because their physical condition limits the carer’s ability to move them from indoors to the outside world. Again, the respondents seem to fatalistically deny themselves the right to such opportunity because of their physical limitations. A controlling factor is the bedtime routine built into care packages. Many carers do not work beyond 10 pm and with a number of older people to get into bed, some are inevitably resigned to their bed very early in the evening. Consequently, they are unable to engage in any evening activities in their community (Patmore, 2004). Sykes and Groom also report how the lack of continuity of care staff impedes relationship building. As soon as trusting supportive friendships have developed with carers, rotas are changed and staff are reassigned, leaving the older person profoundly affected by the loss. In their study of adjustment and containment within the home care setting, Athlin, From and Johansson (2007) report how older people believe it is possible to have a sense of psychological well-being at the same time as having a physical or mental disability, but that there were barriers preventing them from realising this potential. One of these barriers was the lack of social inclusion and

feeling a sense of “togetherness” versus “being an onlooker” (p. 282). The former made them feel respected and valued, whilst the latter resulted in feelings of loneliness and powerlessness. McLeod (2008) investigated a voluntary social rehabilitation project set up for people making the transition from hospital to domiciliary care. Through his qualitative study with 17 older people and 5 project coordinators, he evidenced that, at this juncture, service users benefited both in terms of physical health and psychological well-being when engaged in social networks. Supporting this principle, Pino et al. (2014) found that older people thrive better when they are socially integrated, and that social isolation contributes to poorer health and psychological well-being and impedes recovery following illness.

Gethin-Jones (2012a) carried out a comparative study of the relationship between individual subjective well-being, and both the traditional task centred and outcomes-focused models of domiciliary care. He identified feelings of disconnection and isolation when the care is delivered using the traditional model, with many participants reporting their inability to leave the house as their main source of stress. However, Gethin-Jones (2012a) reports that with outcome-focused care, participants were able to ‘bank’ enough hours of care to be taken out to the community and they developed a more focal relationship with their carers and had a greater sense of well-being. Patmore and McNulty (2005) sought to identify and promote opportunities for care organisations to provide flexible person-centred care that would meet the standards within the National Service Framework for Older People (DOH, 2001). They highlighted the potential, through supporting older people with limited mobility to engage in community activities, to both aid recovery and prevent depression (standard 7, p.90) and to promote a healthy active life in old age (standard 8, p.107).

3.4.2 Autonomy in care

The United Kingdom Homecare Association resource guide (2006) states clearly that service users should be afforded control over their own lives, and be able to make choices about everyday activities. The inter-relationship between disability, mental health and autonomy within the home care system has been the subject of many studies. Having self-determination, independence and control have been found to be the strongest predictor in the absence of depression amongst older people (Reker, Peacock and Wong, 1987). Autonomy was further defined by Collopy (1995) in drawing the distinction between decisional autonomy and executional autonomy, that is the ability to make decisions about one’s care and furthermore

the ability to actually bring those decisions to fruition independently. Boyle (2005) explored the role that autonomy plays across long-term care settings and found that decisional autonomy plays a greater role in the psychological well-being of older people in the home-care setting than executional autonomy. She interviewed residential and home-care older service-users in Northern Ireland and concluded that it is not so much the physical impairment, and the inability to execute self-determination that affects psychological well-being, but more the constraints placed upon older people with regard to their everyday life regimes. Furthermore, she reports that the home-care setting places greater restriction on decisional autonomy than the residential care setting, with older people at home having little choice, for example, about when they can bathe, what they can wear, or when/if they can attend religious services. She did suggest however, that older people may relinquish their decisional autonomy through a reluctance to challenge the decisions made by the carers, although she does not explore the reasons why they may acquiesce in this way.

Sykes and Groom (2011) discuss how some older people felt they had little control over the allocation of the care provider, and limited input when it came to the building of care packages. Karlsson et al. (2013) explored care satisfaction among older people receiving care at home and in special accommodation. They report low rated self-care satisfaction especially when the recipient has little influence over their care arrangements and they feel they have lost. Sykes and Groom (2011) report how older people feel frustrated with the lack of flexibility afforded to them by the carers with regard to daily activities, for example the time they are put to bed and helped to get up again the following day. The authors demonstrate how the age old conflict between paternalism and autonomy manifests itself within the care environment. At this point I became interested in the ethics surrounding the issues of power within the caring relationship and how an individual's autonomy can be compromised when their vulnerability threatens their ability to make their own choices. I looked towards influential texts. In defining individual autonomy, Locke claimed that the individual “has a right to decide what would become of himself and what he would do, and as having a right to reap the benefits of what he did” (Locke, 1689, cited in LaFollette, 2002, p.536). However, Mill, in exploring “the nature and limits of the power which can be legitimately exercised by society over the individual” stated that “those who are still in a state to require being taken care of by others must be protected against their own actions, as well as against external injury” (Mill, 1859, cited in Hendrick, 2000, p.175). Sykes and Groom (2011) report older people taking a passive role in their care delivery, and having low expectations about their

rights to quality care. They argued that this may be because professionals, family and friends consider that either older people do not have the faculties to be able to decide what is best for them, and that they know best

Another area of autonomy that is discussed in literature refers to personal home and body space. Nordenfelt (2009) suggests that autonomy enables the preservation of the sense of self, and Dyck, et al. (2005) looked at how the caregiver's entry into the home challenges personal identity through its invasion of the home space and the physical body. They describe how the home "is a crucial material and symbolic source in the construction of personal identity" (p.174). It becomes an increasingly significant part of an older person's life at the very time that their social and geographical world shrinks due to limited mobility and increasing illness. However, it is at this vulnerable time that the home is reconstructed into a care-giving space, with the possible introduction of intrusive care equipment, and where the boundaries between the private self and the social self become clouded. Healey-Ogden (2014) draws upon her findings from a hermeneutic phenomenological study of the experience of well-being, to explore how care practices, well-being and the meaning of home within a care environment together interact. She suggests that the essence of the family home can change to such a degree that the older person feels they have lost control, and the home "takes on the characteristics of the skeleton of a house rather than the nurturing nature of a home" (p.76). Dyck et al. (2005) explore how the body becomes a site of blurred boundaries, where personal care including toileting, cleaning and dressing invades the intimate and creates a dependency and vulnerability that is not always carefully managed by carers. The Equality and Human Rights Commission survey report discusses how home-care is, by its very nature, intrusive with regard to both the home space and the body space, and how some older people reported disturbing examples of disregard and lack of respect where care workers fail to recognise and acknowledge the older person as an individual. However, Sykes and Groom (2011) report that, in spite of the intrusions that domiciliary care necessarily brings, the majority of their respondents resisted the idea of leaving their home to move to a residential setting. Whilst having domiciliary care signalled for some a move away from independence, these intrusions were outweighed by the attachments they had developed to their home.

3.4.3 Carers' ways of working

As my review has highlighted, there is an increasing demand for person-centred care that moves beyond the physical domain and considers their psychosocial needs. I will now explore how strategic decisions made at the organisational level about the way in which care is delivered may have a direct impact on the older person, In Chapter 2 I discussed the policy context surrounding the development of task-centred and outcomes-focused models of care. I now present evidence of how care delivery based on both models have impacted on an older person's psychosocial needs.

Many authorities continue to follow a rigid task-centred model (Gethin-Jones, 2012b, Oxford Brookes University, 2012). The Equality and Human Rights Commission report that this way of working threatens the older person's human rights. When carers are allocated tight narrow time bands for carrying out activities such as dressing, bathing and preparing meals, there is no room for flexibility to meet individual needs. There is little room for service-user choice or autonomy when there is just not the time for the carer to deviate from the list of tasks. Francis and Netten (2004) in their qualitative study with older people and professionals report that flexibility was an important aspect of care delivery. Yet they cite examples where carers are unable or unwilling to deviate from the care plan to help with tasks such as hanging out washing, helping with filling out forms or arranging GP appointments, as they are not on the job sheet. When challenged, the care organisations expressed frustration with uncompromising, inflexible and cumbersome social services contracts. Any change to the task list must be reported to the commissioners, with the likelihood of a new time-consuming and intrusive assessment of needs. Sykes and Groom (2011) cite older people's experiences of carers rushing through a list of jobs with little communication as though the older person was being processed rather than being cared for. The Equality and Human Rights Commission report instances where an older woman was left on the toilet whilst the carer prepared lunch, leaving her to get herself unstuck from the toilet to make her way downstairs. Conversely, they also cite an example where the carers insisted on washing and dressing a lady even though she was capable of doing this herself, simply because these tasks were specified in the care plan. Their inflexibility not only denied her one area of independence, but also failed to acknowledge she needed help in other areas of her life. In his longitudinal study, Gethin-Jones (2012b) compared the care received by two groups of older people, one group being cared for using the task-centred model and the other using outcomes-focused

model. Where traditional task-centred interventions were employed he quotes examples such as:

“I ask the girls all the time, that when it is nice could they just help me to sit out for 10 minutes, but they just say if it’s not on their schedule (care plan) they can’t do it” (p.82)

“Well it’s not on my care plan, so nothing has changed. I spoke to the social worker after your last visit; she said I would have to fund anything like that myself, and she would arrange it. But she hasn’t been back since, and she never responds to my calls. I’m so fed up I need to get out.” (p. 83).

However, for the group where outcomes-focused care was delivered, the reports were somewhat different. For example, one older person felt able to shave some time from the personal care duties afforded him, and banked up some hours for activities that met his non-physical needs. :

“Well it is great I get one and a half hours every fortnight. I went to the park last week and the newsagents before that. John is still running it and remembered me which was nice. I felt that I was still part of things when John recognised me - it was great.” (p.80)

It seems that flexibility of care, inherent in outcomes-focused models and yet sadly lacking in the task-centred methods employed by many authorities, is a vital ingredient for feelings of self-esteem, autonomy and social inclusion. The older person’s perspective across these studies is that they are unhappy with rigid standardised care plans that fail to recognise and adapt to their individual and dynamic needs.

There seems to have been positive developments at the rehabilitative level with older people leaving hospital with a care plan that is very much outcome-focused (Equality and Human Rights Commission, 2011). Glendinning et al. (2008) identified outcomes-focused initiatives around the delivery of home care services to older people who were in need of intensive support following hospital discharge. However, Gethin-Jones (2012b) opines that whilst the short-term outcomes methods have proved successful in speeding up recovery and limiting hospital bed-blocking, once the outcomes have been met the older person is transferred to the local authority’s traditional task-centred methods of care.

Whether care is delivered following the task-centred model or using outcome-focused methods, the continuity of staff has been identified by older people as an important aspect of

their care. Sykes and Groom (2011) report older people, complaining about the stress of having to explain care duties to a constantly changing stream of carers. The Equality and Human Rights Commission (2011) quote one older person feeling their personal dignity is not respected when there is a constant stream of new staff entering the home. Francis and Netten (2004) also report that many of the older people they interviewed saw continuity as a valued part of care service. Furthermore, the Care Quality Commission (2013) claim that often older people received no advance notice that they would be visited by someone they had not seen before, and that they would much prefer the same care workers who know and understand their individual needs, preferences, and physical competencies. However, Gethin-Jones' research (2012a) found that the group receiving outcome-focused interventions experienced greater continuity of staff and developed positive relationships with carers:

“It is so different to the previous lot (time/task), I see the same faces regularly and they know my little ways and it is good, yes a good relationship I think.” (p.84)

Gethin-Jones goes on to claim that this consistency of care staff was not intentional but came about only because management found it easier to allocate the same staff to outcomes-focused interventions. It was not a planned objective and could not be guaranteed to continue. Francis and Netten (2004) claim that managers have difficulties in recruiting and retaining staff and struggle to cover unauthorised and unexpected absence in order to maintain the continuity so needed by older people. The consequence of high levels of staff-turnover and the frequent juggling of rotas to cover absences, is that relationship building is difficult to achieve and often older people feel bereft when a carer leaves the agency or is transferred elsewhere to another client (Sykes and Groom, 2011).

Another major concern expressed across literature is the time of day when carers are scheduled to visit and whether they in fact arrive on time (Francis and Netten, 2004). Sykes and Groom (2011) cite an example of one older man being put to bed as early as 7.30 pm and suggest that older people feel socially excluded when being forced to spend evenings in their beds away from friends and family. Furthermore, many older people are unable to take themselves to the toilet and are left from early evening until the next morning in soiled incontinence pads. Regarding time-keeping, Francis and Netten (2004) report managers complaining that the timings of calls are impossible to manage whilst contracts do not allow travel time between carer's visits. When time is so tight, any problems with traffic, for example, cannot be accounted for and managed. Furthermore, care providers claim that such

tight hourly rate budgets do not afford them the opportunity to pay on-call staff to provide backup, or to manage unforeseen difficulties in arriving punctually with the next client.

In this final section of the review I have looked at the importance of caring for older people in a way that respects their individuality. Such care promotes personal dignity and reduces social isolation, and the attitudes of care staff play a significant role. Furthermore, I reveal the pivotal role that care plays in supporting personal autonomy and, in particular, with regard to making decisions about who provides care and how it is delivered within the home, including respecting the home and body space. The management of care also impacts heavily with literature citing the continuity of staff and the timing of calls as contributory factors. Moreover, task-centred care continues to be the preferred model for many Local Authorities yet the advantages of outcome-focused care is evidenced.

It seems then, that, in spite of numerous reviews, reports and recommendations, there are still care practices that fall short in acknowledging the importance of self within care. There is still much to do if domiciliary care is to recognise that issues such as autonomy, dignity and individuality are important to older people. They need to retain some control over their lives and be afforded care that respects their very personal and idiosyncratic needs and wants.

3.5 Summary of the review

Threading through this review has been the concepts of self and identity. I have presented an understanding of self based on the life stage model, and have found that in older age there are tensions in the struggle for integrity over despair and, later on, trust over mistrust. Furthermore, skills and strategies that have been accumulated through the earlier stages of life help the individual to reach ego integrity and ultimately to trust themselves and their environment to support them as their personal resources decline. Research by Hvalvik and Reiersen (2011) indicate that older people gain strength from recognising and understanding how past experiences have helped to develop personal strengths. Similarly Janssen, Van Regenmortel and Abma's (2011) evidence that older people were better equipped to manage the difficulties they faced when they had a sense of pride at how they have overcome challenges.

Whilst acknowledging the individual domain, I have also explored how self is supported through identity with others, through salient roles. Self emerges, develops and is sustained only within a relationship with others. Janssen, Van Regenmortel and Abma's study (2011)

evidences the importance placed by older people receiving care at home on feeling part of their community and how they gained strength from feelings of mutual responsibility and solidarity. At a time when roles are reducing due to physical limitations, the relationship with the carer becomes even more significant and the role of cared-for becomes salient. Abad-Corpa et al (2012) and Hvalvik and Reiersen (2011) stress the importance of a positive care relationship in promoting feelings of self-esteem, competence and self-worth. There are opportunities in this relationship to support the older person to reflect on past experiences and to acknowledge the strengths that have developed.

Similarly there are opportunities for carers to recognise and understand the different ways in which people experience getting older. Kaufmann's theory of agelessness (1994) suggests that old age is not a distinct period in life but rather a continuity of the ageless self, a notion evidenced by the study by Rozario and Derienzis (2009). Furthermore Kaufmann espouses that it is this view of the constant ageless self that mediates the demands of change. Yet Andrews argues that such a view is ageist and that older age should be celebrated, older people should be valued for their life experiences, and that in fact some older people do feel old as they face the challenges of infirmity. Featherstone and Hepworth (1989) also suggest that it is not always easy to see through the mask of ageing to understand and appreciate the inner person. These range of theories only help to reinforce the notion that ageing can be experienced very differently. Yet understanding how a person experiences getting older can support fruitful caring relationships and help to resolve the integrity vs. despair issues being faced. Furthermore, care can support the 9th stage and Wadensten and Carlsson (2003) propose practical measures that can be taken by carers to identify and support signs of gerotranscendence.

In section 3.3 I discuss the external factors that influence the care that older people receive at home. I explore how an understanding of the ageing process has the potential to be very different when viewed from the older person's perspective, and from that of the carer, the care organisation and society. This is particularly relevant when set within a political and economic context that has more than solely the interests of the individual at heart. Yet these views have a direct impact on an older person when being cared for in their own home. Care practices have the potential to construct and reinforce stereotypical ageist identities of older people, as reinforced by the studies of Minichiello, Browne and Kendig (2000) and Hoban et al. (2013).

In summary, through this review I have explored a range of theories and understandings of self, identity and ageing in order to understand how care interacts with self. Some studies such as those by Fischgrund (1975), Christiansen and Baum (2005), Abad-Corpa et al. (2012) and Janssen et al. (2011) take an interactionist position, focusing on how the relational environment of care and the roles that are enacted affect the experience of care. Others like Hvalvik and Reiersen (2011) and Perry et al. (2014) focus on the personal domain, looking at the extent to which earlier life experiences contribute to the management of the challenges faced in later years. Whilst these very different theoretical positions offer up their own understandings of the older person's experience of care, I argue how they can be complementary in the context of this study. I have also explored a range of ageing theories, looking at how older people experience getting older and how external forces can affect that experience. Furthermore, I have looked to literature to discover how current care practices and the ways in which care is delivered impacts on individuality, autonomy and dignity. Hence, through my review of literature and my presentation of a range of theories I have begun to develop my conceptual framework (see figure 5).

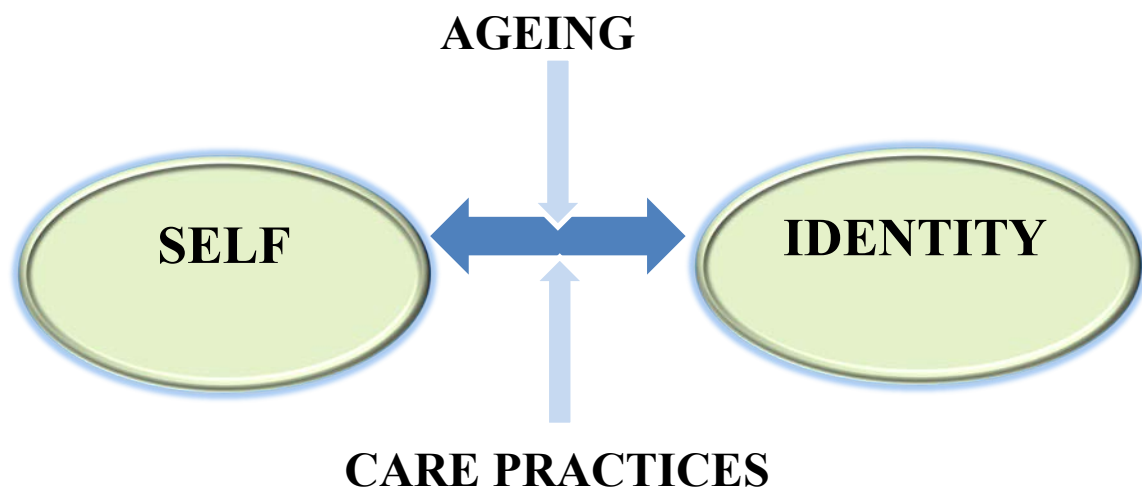


Figure 5: Conceptual framework

Chapter 4

Methodology

4.1 Methodological position

The purpose of this research is to understand the ways in which domiciliary care considers sense of self, how older people feel about the care they receive and whether care practices have any impact on an older person's autonomy and how important this is for maintaining self within the caring dynamic. It was important therefore for me to collect data directly from older people in receipt of care at home. I wanted to hear their voice, and to understand from their perspective what it feels like to be in a position of care and how they feel it affects their sense of self.

To fully grasp how the older person's self may be affected by domiciliary care, it will be necessary for me to first explore the circumstances surrounding their personal and individual journey into a position of care, and how they feel their change in circumstances has interacted with their self.

4.1.1 The narrative enquiry

Narrative inquiry provides a way of gathering, investigating and analysing stories of experiences and events. Storytelling is the most common form of human communication (Webster and Mertova, 2007) and the narrative form is the universal way in which people communicate and re-interpret and make sense their life experiences. It can be used as a way to gain insight into the complex relationship between these experiences, the meanings that people apply to them, how they respond, and social and societal contexts in which they occur. (Andrews, Squire, Tamboukou, 2008). Being guided by Wengraf (2000) and Plummer (1995), I decided that this would form the backbone of my methodological approach.

In order to fully understand the ways in which the older person is affected by care practices, I extended the narrative to a dynamic record of daily activities and I explored literature looking for other researchers' experiences of using the diary in this way. I took inspiration from Jacelon and Imperio (2005), Alaszewski (2006), Elliot (1997), Zimmermann and Wieder (1977) and Milligan, Bingley and Gatrell (2005). I decided that the older person's dynamic diarised account of care practices and how they interact with self, how they promote feelings

of dignity and autonomy would complement my methodological approach. A combination of the narrative and the diary would be the best way to capture the older person's voice and to gain some real deep insight into their interpretations and understandings of the care environment.

Finally, I will complete the enquiry by exploring, through the follow-up interview, the incidents of care, and their interaction with self against the backdrop of the narrative. I would discover how the older person feels about the incidents they have recorded and how they have interacted with how they see their selves. In essence I would find out how they feel the care they receive has affected who they are, and if so those incidents of care that are salient, and whether or not they feel that their self endures through the process of care and remains unchanged.

I explored literature and whilst I found little evidence of such a three-pronged biographic-narrative/diary/interview approach, I was guided by Zimmermann and Wieder (1977) and Elliot (1997) who provided useful insight into the benefits of using the follow-up interview following a period of diary collection. Consequently, I followed a biographic-narrative/diary/interview research design. This would be the ideal model, placing the older person at the heart of the study and capturing dynamic diarised data and allowing reflection and exploration of the interaction with self. My research design has been guided very much by not only my own ontological (nature of reality) and epistemological (how we know what we know) position, but especially by the research questions. The design best fits the nature of the phenomenon under discussion and the questions that are posed

4.1.2 Ontology

Ontology is concerned with the form and nature of reality and, therefore, what is there that can be known about it however, within the positivist paradigm, there is a single objective reality that stands independently from human cognition. It can be clearly defined and understood through a methodology that is rigorous and scientific based on universal laws, objectivity and neutrality (Cresswell, 2013). To the positivists, knowledge beyond what can be seen and observed is impossible and that detachment from, rather than participation with the world they study, allows them to explain and predict what is happening by seeking out causal relationships and regularities (Green and Brown, 2005).

However, within the constructionist paradigm, and one in which this study is firmly rooted, truth and reality can never be truly known and that

"all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (Crotty, 1998, p. 42).

Reality is therefore constructed from the individual's perspective and as such social phenomena and their meanings can never be definitive and there are no universal truths (Bryman, 2001). They can only be understood in terms of that unique perspective and within a specific range of by personal, historical and socio-cultural contexts. Realities are therefore multiple, intangible, relative and constructed, and as such are local and specific by nature and whilst contexts are alterable, so therefore are their realities. Unlike the positivist view of the world, for a constructionist there is no one unique world that exists outside of human interaction. Consequently, in taking a constructionist stance I knew that my methodology should not be based on a quantitative style of aggregation that would be "insensitive to uniqueness and difference" (Rodwell, 1998, p.18). Establishing any validity based on external criteria would be futile and that meaning is preferable to measurement (Krauss, 2005). I also knew that in conducting the research I was therefore also embedded within it and that my preconception as an individual would impact on the research.

The biographic-narrative/diary/interview method of data collection allows me to explore from a constructionist position the unique world of the participant and to gain rich and valuable insight into the way in which the older person views their journey into a position of care and how they see themselves within that context.

4.1.3 Epistemology

Epistemology is concerned with the theory of knowledge. That is, how we know what we know, what the relationship is between the knower and what is known and what counts as knowledge (Crotty, 1998). Again, whilst the positivist epistemological approach is one that seeks out scientific rigour, credibility and objectivity through direct observation and measurements, the philosophical position of this study is one that takes a more relativist and interpretive approach. Truth or meaning comes into existence in and from our engagement with the realities of the world. Knowledge is context and time-dependent in that it is constructed when people interact with their world and that knowledge is expressed within

social context and “social actors are seen to jointly negotiate the meanings for actions and situations” (Blaikie, 1993, p.96). Knowledge is idiosyncratic and constructed as our cognitive systems take the information from our social worlds and screens, translates, alters or even rejects it applying our own meaning to what we are receiving. Schwandt (2000) explains it further:

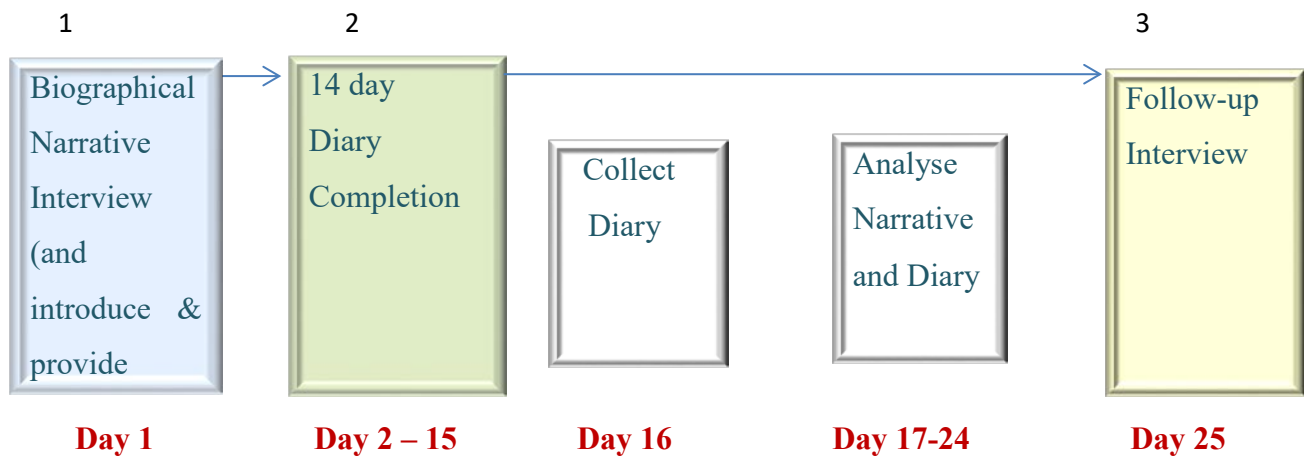
“most of us would agree that knowing is not passive - a simple imprinting of sense data on the mind - but active; that is, mind does something with these impressions, at the very least forming abstractions or concepts. In this sense, constructionism means that human beings do not find or discover knowledge so much as we construct or make it” (p. 197).

Of course a further difference between the positivist and constructionist epistemological positions is that whilst the former strives to remain detached from the studied reality, the latter naturalistic view is that the researcher and the researched cannot remain separate, they are joined in such a way that the knowledge acquired is intrinsically a part of the process and that knower and known are created together through the enquiry.

In using the biographic-narrative/diary/interview method I am able to explore social contexts through which knowledge is acquired, both through the narrative enquiry and with the diary, looking at examples of interactions between the older person and the carer and at the organisational level with the care system. Again using the follow-up interviews I can explore how the older person applies meaning at the point of interaction and how this impacts on their sense of self.

4.2 The Data Collection methods

The data collection therefore takes a three stage approach (see figure 6).



*Figure 6: A logical representation of the Data Collection Process
(N.B. the days may not be consecutive)*

I chose this three stage approach of the biographical-narrative, the diary and the follow-up interview, because each method would be revealing in its own right and yet together they provide me with answers to my questions. The biographical-narrative would allow me to understand how the participant has managed the stages of life and ultimately into the caring domain, and how they view their enduring and evolving selves as they look back on their lives (Wengraf and Chamberlayne, 2006). The diary on the other hand is a conduit for the current and dynamic expression of their thoughts and feelings about incidents of care (Elliot, 1997). Finally in the follow-up interview, having analysed data from the first two stages I am able to draw on their personal history and their development of self, and tie this in with their diarised accounts to gain an understanding of how care practices interact with self and promote feelings of dignity and autonomy.

Research with older people has taken many forms and there have been examples of the diary-interview approach (Jacelon and Imperio, 2005, Milligan, Bingley and Gatrell, 2005) but I have limited evidence of a biographical-narrative/diary/interview method employed in research with older people and specifically within the context of care. Yet for me it is just as important to understand, through the biographical-narrative, the person as a whole and what has influenced and affected them as they have moved into the cared-for role, as it is to explore the current day to day realities of care through the diary. Similarly, the follow-up, semi-structured interview gave me the opportunity to ask questions across the first two domains, to follow up on themes, and to gain clarification of accounts of practices and meanings that may be inconsistent.

For example, one participant said that she had been a gregarious, independent and confident younger person yet recounts in her diary that she feels, in her old age, that she has lost her dignity and autonomy. I was able to explore through the final interview what care practices make her feel that way, and when she reflects back on her past, how she reconciles what she sees as the very different version of herself with the one that she sees now.

4.2.1 The biographical-narrative

Narrative and biographical methods have become increasingly ubiquitous within social science research “pris[ing] open the different dimensions of lived totality” (Gottfried, 1998, p.452). In a post-positivist climate, it is the *personal* as well as the *social* understandings of the lived experience that have gained prominence (Wengraf, 2000).

Plummer, (2001) suggests that within the field of social work, the telling of stories allows a greater understanding of how individuals function and communicate within their social context, challenging taken-for-granted beliefs and assumption. Whilst each biographer’s story is unique, it is embedded within a social and cultural context and through the biographical narrative we are able to gain insight into not only the individual’s idiosyncrasies but also the “particular social structures and dynamics and cultural values, morals and norms in which the individual lives” (Chaitin, 2004, p.3).

The narrative not only allows the researcher to gain insight into the narrator’s social and cultural identity, but through constructing stories about their life, the narrator is imparting, receiving or affirming meaning to life experiences (McAdams, 2001, Pasupathi et al., 2007). McAdams, (2001) suggests that through such constructions the narrator is able to draw connections between the self and earlier life experiences and thus achieve greater self-awareness and self-development leading to greater stability in the how they view themselves. McAdams and McLean (2013) propose that when the narrator can apply redemptive meaning to negative experiences from the past, and develop a greater understanding of self, they enjoy improved psychological well-being and increased generativity. Thus the narrative process is itself constructionist (Bluck et al, 2005).

The first stage in my work with participants was to explore, through the biographical-narrative, their lived experience of care and how it interacts with their sense of self, asking them to talk about their lives since they have been older and how they have managed the transition from independence to being in a relationship of care. However, I was not merely

interested in taking an individualistic stance but returning to the concept of role theory, I set out to gain insight into the relationship between the cared for and the carer, between the individual and the wider structures with an emphasis on the construction and enactment of identity. As Wengraf and Chamberlayne (2006) explain in their introduction of the biographic-narrative interpretive method, the process

“facilitates understanding both the ‘inner’ and the ‘outer’ worlds of ‘historically evolving persons in historically evolving situations’ and particularly the interactivity of inner and outer world dynamics” (p. 1)

Building on the conceptual framework developed so far in chapter 3 (see figure 5), I saw the biographical-narrative stage of my research as the first step in the understanding of the way in which social constructionism, symbolic interactionism, role theory and Erikson's psychosocial model have evidenced across people's lives. Theory can help us to understand and interpret life's experiences and specifically, for the purpose of this research, how the enduring self supports the transition into the caring relationship and the extent to which social context through symbolic interactionism impacts on identity.

Erikson speaks of the 8th stage of integrity vs. despair and Joan Erikson speaks of the 9th stage of mistrust vs. trust. I was keen to hear people's stories about how they have felt since being older and particularly when faced with re-evaluations, demands and difficulties brought about by physical and mental limitations. I also explore through the biographical-narrative how participants have negotiated their way through the stages of life and the extent to which successful or unsuccessful negotiation of earlier stages has impacted on how well the older person manages now. I focus too on how they have managed the transition from the 7th stage of generativity vs. stagnation into stage 8 and, in particular into a position where they are receipt of care, and ultimately onto stage 9.

As I have explored in the literature review, there may be a ‘ground plan’, an internal biographical continuity, with the self persisting through the stages of life, a self that negotiates life's transitions. Constructionism may play a role too at the interactional level with family, with friends, in the community and with care professionals, and within the contextual political and societal domains. I set out, through the biographical-narrative, to understand how the older person views the things that are happening in the context of care, the level of agency they retain in the expression of their identity, and what importance they place on different aspects of the care environment. Symbolic interactionism offers a

theoretical interpretation of how older people process and understand the situation that they find themselves in.

Biographical-narrative enquiry is open-ended (Wengraf, 2000, Chaitin, 2008). I began by introducing myself and reminding the participant of the purpose of the research using the Participant Information Sheet (PIS) (see Appendix 2). I gained consent using the Participant Consent Form (PCF) (see Appendix 3). To elicit the narrative I asked a broad open question that would allow the informant to develop a long story from an initial state of affairs, through past events, leading to the present situation (Jovchelovitch and Bauer, 2000, for example, “How have things changed for you since you have got older?” (see Appendix 4A). I remained quiet whilst the participant spoke about their lives, providing supportive prompts if they needed guidance or struggled to start. I knew I had to resist leading the participant in any way, allowing them to choose freely what they wanted to speak about (Elliot, 2005). Whilst this meant that at times the narrator may have wandered off in to areas that may appear irrelevant to the study, I was interested in how they had negotiated their way through their lives. Even the most seemingly irrelevant story may hold some value at a later stage of analysis (Thompson, 2000). It was important that my opening question did not govern or dictate the way in which the story was told, but that the participant was able to tell their own story. The significance they place on aspects of their lives can also in itself be revealing (Mishler, 1986). When they had finished telling their story, I did, however, return to particular areas of interest, or where I felt I needed more explanation that would provide me with a good account of who they are and how they have managed throughout their lives. I ensured I did not ask ‘why’ questions at this stage, preferring to explore using questions preceded by ‘what happened’, for fear of appearing critical or judgemental (Jovchelovitch and Bauer, 2000). Similarly I avoided pointing out any contradictions that may have occurred through the narrative. The purpose of this questioning phase of the narrative is to draw out new and additional material beyond what has been told through the story.

Fraser (2004) suggests a conversational, friendly relaxed style of narrative engagement, with blurring of boundaries between the narrator and the listener, resisting the urge to interrupt or re-focus and of ‘hijacking’ the conversation (Thompson, 2000). I was also sensitive to when the participants became distressed when talking about their lives, for example about losing a partner, and I gave them the opportunity to take a break. I was also aware of time and how some older people may become tired. Talking about their lives may deplete their energies and

that the effects of this may last beyond my visit. I was vigilant for signs of fatigue, and offered to take a comfort break or to return at a later date.

I also recognised that I had a responsibility as researcher to provide support if the participant became distressed when discussing sensitive or upsetting subjects as “if we undertake to study human lives, we have to be ready to face human feelings” (Ely et al., 1991, p.49). It is vital that the researcher is caring towards the participant during the research process and that the researcher expresses a “commitment of self” (Noddings, 1984, p.13). Dickson-Swift et al. (2007) record how when a participant revealed something particularly intimate the researcher decided to switch from researcher to just 'being' with the participant:

“When he became so upset I switched the tape recorder off and in doing this there was real shift to the personal. I stopped being a researcher and I became another person in the room with him, I gave him a hug, we had a cigarette – it was much more human.” (p.336)

However, I was conscious of how the boundaries between myself as researcher and the participant may become blurred and the risk of it developing into a therapeutic relationship (Dickson-Swift et al., 2007). I found this a challenge particularly with one participant who was reaching the end of his life. Both he and his wife looked to me for emotional support and practical advice regarding hospice care, housing and finances. I carefully referred them to the appropriate services trying very hard not to be dismissive or uncaring, whilst at the same time recognising that I was not qualified to provide emotional therapeutic support and I did not want to create a situation of dependency. Once my data collection process was complete, the relationship would come to an end.

On the other hand I also knew that, following the biographical-narrative interview, I would be returning to the participant's home on a further two occasions, to collect the diary and to carry out the follow-up interview. It was essential that I developed a rapport with the participant and established a trustful and respectful relationship (Merriam, 2014). This first encounter would set the scene for the following data collection stages and the biographical-narrative therefore provided me with not only valuable and vital information about the participant's history and how and why they are now in a position of care, but also had the potential to develop a relationship of trust that would make them feel more confident about allowing me back into their home.

4.2.2 The diary

The use of the spoken and written narrative has been increasingly employed in the exploration of health experience (Dunn and Bercaw, 2013, Thomas, 1999, Grinyer, 2002). With regard to the diary, Milligan, Bingley and Gatrell, 2005 describe it as another tool in the narrative toolbox, a tool that provides a means for collecting rich qualitative data that tells the participant's own story and to "record an ever-changing present" (Plummer, 2001, p.48). Alaszewski (2006) provides a detailed historical account of how diaries have been used across disciplines, and how they have been employed within both quantitative and qualitative studies. The solicited and structured diary has been used within the medical profession for many years, although in very much a quantitative fashion, with checklists and logs that resemble the survey technique (Milligan, Bingley and Gatrell, 2005). Yet the diary and in particular the less structured solicited diary is a tool that remains relatively under-used within social science research (Jacelon and Imperio, 2005, Johnson and Bytheway, 2001).

There are differences between the unsolicited and the solicited diary. A personal unsolicited diary is an "intimate journal" (Madge, 1953, p.83) written for the benefit of the author and is usually private and not for the consumption of others. It is

"a personal document, written without overt financial or other inducements, that attempts to construct a picture of the actor's perception of social reality with regard to events or constructions of events, very much a personal spontaneous and contemporary account" (Jones, 2000, p.558).

In an unsolicited diary the author chooses the entries, deciding on what is important. In recent years, perhaps due to the more widespread use of technology and the internet, there has been an exponential growth in the number of narrative, anecdotal and idiosyncratic commentaries of illness written by individuals of their own volition. These accounts have proved invaluable in the understanding of how people experience illness (Bingley, et al., 2006). However, they are very much narrator driven, focusing on issues of greatest importance to the writer. However, the solicited diary, as used in this research, is one that is written by the diarist at the instruction of the researcher. It is not private, is written for an audience with a particular agenda in mind to elicit specific information, and the diarist will have a strong awareness of the researcher and how they will receive their writings.

It is also worthwhile pointing out the difference between the structured and unstructured diary. Like Milligan, Bingley and Gatrell (2005), DeLongis et al. (1992) record how structured solicited diaries can resemble check lists and surveys, collecting quantifiable data

and report how they have been used extensively within health research. Following the qualitative tradition, the less structured diary generates more personal accounts, eliciting thoughts and experiences that are often restricted by the pre-coded categories of the structured design. However, as Hyldegård (2006) points out a degree of structure is necessary, alongside clear instructions for completion, in order to manage the amount of data and its validity and reliability, a matter I will return to when I discuss the way in which I presented the diary to research participants.

I reflected carefully on how I was going to collect the data before deciding to use the diary approach. Observation would have been my preferred choice, but as Alaszewski (2006) points out, the observation process has potential to disturb the relationship of care and distort the very data I seek to obtain. The context of care can also involve very personal tasks, such as toileting and bathing, and my presence as an observer would have been unethical, placing unnecessary stress on participants. Bloor (1985) also found that his observations of illness behaviours provided only random and partial insights. However, Zimmerman and Wieder (1977) suggest that the diary can act as an observational log, placing the participant subjectively at the very heart of their experiences, and is

"their definition of the situation, and includes their attitudes, beliefs, evaluations, boasts, complaints and so forth all of which adds the critical subjective dimension to the naturally occurring activities he witnesses" (p.483).

I also felt that in completing the diary in their own homes, at the "heart of social contexts" (Meth, 2003, p.199), participants would have the opportunity as they write to contextualise the entries, as they engage with their on-going social realities, realities that may be difficult for the researcher to access. As Elliot explains

"..the potential to use diaries as a vehicle for research informants to observe situations which researchers cannot access has been explicitly drawn out within the context of ethnographic research" (Elliot, 1997, p.4).

I was also concerned about memory recall. If I had used the interview method in isolation I was aware that participants would not remember what had happened, and more importantly how they had felt. Retrospective accounts rely wholly on the participant's power of recall. Recording activities, behaviours thoughts and feelings close in time to when they occur not only reduces the impact of time on memory, and in turn the number of recall errors, but also

facilitate the capturing of events that may be seen as trivial and unimportant and thus forgotten over time (Verbrugge, 1980).

Meth (2003) also suggests that writing a solicited diary meets the feminist principle of empowerment and of giving a voice to those who may be unheard. However, the purpose of my research was not to empower. I was conscious that I should not only avoid entering into a therapeutic relationship as I did not feel qualified to do so, but I did not feel confident in making promises that I could fix whatever may be wrong with the way in which care was experienced. Yet some participants found the process of diary writing helped them to express process and understand their thoughts and feelings about how they were situated within the care relationship, a matter I will explore in the next chapter. However, I was also aware that participants may write about matters that were sensitive and upsetting, and I gave them an opportunity to mark that page with an asterisk so that we could explore it later at the follow up interview if they more comfortable doing so.

Some people like writing diaries, some hate it and some like the idea but struggle to keep going. I recall many years when I have been given a diary for Christmas. I promised myself that I would write in it every day for the whole year, only to find that by the middle of January I find it a chore and a burden. Motivation is an issue, and Sheridan (1993) suggests that some are predisposed diarists, who keep records, collect memorabilia and like the idea of preserving what happens now for the future reader. On the other hand Elliot (1997) reports one diarist who gave up after a week, fed up with writing about her 'boring life'!

Competence is also a matter for consideration. Literacy skills play a part in limiting who takes part in diary research. Being able to speak using the English Language does not equip all people with the reading and writing skills needed for diary completion, and I did not want participants to feel coerced into doing something for which they lacked the confidence and the skills. In fact one participant agreed to take part in the research, including the interviews and the diary completion and yet at the end of the biographical-narrative interview she announced she had always struggled to read and write and did not feel confident in proceeding to the diary stage. I reassured her that I understood and would place no pressure on her to continue.

Physical and intellectual impairments might also restrict who can take part in diary research. Johnson and Bytheway (2001) observe that, for older people, visual impairment can make

reading and writing difficult, if not impossible, and even short term memory loss may affect results. I was careful to make it very clear at the outset, to only invite those participants who could read and write in English and who had the capacity to understand the purpose of the research and to be able to recall events.

I was also aware that the diarists within my study had the potential to become not only the observer but also the informant, as diarists are “collaborators in the construction of the account and had a stake in the research process” (Elliot, 1997, p.12). Zimmermann and Wieder (1977) suggest that in asking someone to complete a diary we are asking them to keep a record of not only their own activities and performances, but also those of others, and in doing so we are asking diarists to act as “adjunct ethnographers of their own circumstances” (p.484). I was extremely sensitive to the fact that participants may write something that informs the reader of possible neglectful or abusive care practices. Again I gave them the opportunity to mark the page with an asterisk if they were uncomfortable writing down the details, and to discuss it during the follow up interview if they felt comfortable to do so. Of course it is possible that such events will go unrecorded, as participants are unhappy with their role as ‘informer’, an issue for later discussion with regard to reliability and validity.

The diary is a product of the collaboration between the participant and the researcher. Whilst the participant is the author of the content, the researcher is in control of the design, the layout and the subsequent analysis (Elliot, 1997). I was aware there may be a degree of self-consciousness in the style of writing and that some participants may be reluctant to disclose personal vulnerabilities, or even that their writing may not be of the standard expected for the study, being fully aware that it would be read and analysed by another. I made sure the information regarding confidentiality was clear and that participants understood the purpose of the diary in the study. I also used a style of language that would place them at ease being neither academic, and perhaps difficult to understand, nor simplistic and possibly demeaning. I created a hand-written instruction sheet at the opening page of each diary. I used straightforward language that aimed to put any self-conscious diarists at ease. Writing for an audience can be a daunting task and being very much aware of my ethical responsibilities as a researcher, I used every opportunity to provide reassurance.

I looked to literature for some examples of how to present the diary. Corti (1993) produced a set of guidelines that I found useful and I adapted them to suit my study and my participants.

She recommends an A4 book with about five to twenty pages. I felt that a smaller diary would be easier to handle and feel more personal. In fact I found some A5 sized notebooks with lined pages and attractive front designs that I felt would be more suitable. Corti also suggests placing an instruction sheet at the front of the diary. I hand wrote an instruction sheet for each participant in an attempt to make it feel more personal and stuck it into the front inside cover, making it easy to access. Following Corti's suggestion again, I gave some examples of typical diary entries on the very first page so that participants could remember what kind of information they should include. I was aware that my choice of example entries may 'lead' the participant in some way and I took great care to explain, when I presented the diary, that they were just ideas and may not be typical of the kinds of entries they may make. At the top of each page I entered 'Day 1', 'Day 2,' etc. leaving 4 blank sides per day. (see Appendix 4B) with a total of fourteen days in all. I made it clear that these fourteen days need not be completely consecutively.

I thought carefully about whether some participants may prefer to record their diary using a voice recorder but I decided not to include this option in the participant information sheet for fear of adding complexity and confusion at this introductory stage. However, at the start of each of the first biographical-narrative interviews I did ask whether using a voice recorder to record the diary would be preferable and I had a spare recorder in my briefcase in case the option was taken up. In fact none of the participants took up the offer preferring to use the hand-written diary. There was some nervousness about using technology and I also felt that some participants may struggle to use the sometimes small and hard to see switches at the side of the tiny device. I did explore the market, without success, for a device that would be easy to see, easy to use and have a long battery life. However, it became obvious the more I worked with participants that this was not an option they would like to take up, although I still offered the use of my spare device. I had to be very careful not to make the assumption that being older they would be unable to manage the technology of such a device. In fact one participant aged 82 said that if she did struggle at any time, she would feel confident in using one, although this option was not followed up as this determined and extremely capable lady successfully completed many pages of diary entries.

There has been discussion in literature about the temporal nature of the diary. Jacelon and Imperio (2005), Keleher and Verrinder (2003) and Johnson and Bytheway (2001) all recommend one to two weeks as being the optimal time for keeping the diary. Milligan,

Bingley and Gatrell (2005) suggest that a shorter diary, for example one to two days may not give a big enough window to see typical occurrences across days, but that longer diaries over two months result in diarist fatigue. I felt that in the context of care, with rotas of care being produced weekly and the potential for different carers being allocated to participants, a one week window would not capture a diverse mix of care practices. On the other hand I was aware that beyond two weeks there may be some repetition and possible fatigue and loss of interest. I decided on a two week diary although, as previously stated, I did reassure participants that they need not be consecutive days. I felt this would account for any illness, hospital visits etc.

Johnson and Bytheway (2001) express concerns about the ethics of using dairies in research with vulnerable people. The fact that participants to this study are older and in a position where they need care at home makes them vulnerable. Recording daily life, and in particular the physical and possibly intellectual impairments that may affect daily living, can be stressful, perhaps reminding participants of how their lives have become routine and so different from their younger years (Johnson and Bytheway, 2001). I made it very clear that participants could withdraw at any time without any explanation, and that I would be available at any time if they needed support or reassurance. In fact, I interviewed one participant and presented her with the participant information sheet, the diary and the instructions and she seemed happy and confident, yet she contacted me a week later saying she did not want to proceed. I gently asked her why she had decided against the diary writing but she refused to explain. I found this frustrating, as it would have been illuminating in itself to know why she had made this decision. However, I did not press her and I am left to wonder. Similarly, I visited one lady who was very keen to participate, but her eyesight was extremely poor and she struggled to read the participant information sheet. I felt uncomfortable with her proceeding as I felt it would place undue pressure on her already challenging lifestyle. As Johnson and Bytheway note, starting and not finishing a diary, like any activity, can sometimes be embarrassing, humiliating and possibly more difficult to cope with than not starting at all. Together we made the decision that it would be better for her not to participate for the sake of her well-being. I followed this up with a letter of thanks offering her the opportunity to read the research once it was complete.

4.2.3 The follow-up interview

I contacted each participant after two weeks to see whether the diary was ready for collection. In some cases the diary was not ready as the recorded days were not consecutive and I made arrangements to contact them again

Prior to each follow-up interview I transcribed the biographical narrative interview and typed up the diary. With support from my reflective journal (see Appendix 7 for some extracts) I carried out an analysis of the data in the biographical-narrative and the diary (see section 4.6.2) and generated a list of relevant points for discussion and used them as prompts through the follow-up interview (see Appendix 4C).

I carefully considered the benefits of using the follow-up interview to support the diary and the biographical-narrative. I reached the conclusion that each method in isolation would not give me the information I was seeking. Zimmerman and Wieder (1977) introduced the 'Diary: diary-interview method' in their research of counter-culture in Southern California, believing that the diary is the closest a researcher can get to observing participants without being present and can be used as a basis for exploring subjects within the interview setting. They claim that the interview process in itself would not provide a clear enough picture of what happens on a day to day basis and would fail to provide access to "naturally occurring sequences of activity, as well as raising pertinent questions about their meaning and significance" (p.485). On the other hand the diary used as a standalone data collection method (Milligan, Bingley and Gatrell, 2005) may not afford the researcher the opportunity to explore the content and move into a greater understanding of the thoughts and feelings lying beneath the entries (Elliot, 1997). Zimmerman and Wieder (1977) go on to claim that the effectiveness of the diary is 'undercut' when used in isolation and that there may not only be a difference in depth and details across diaries, but that inconsistencies cannot be explored through the written word alone

The diary proved the best way to capture events as and when they happened. Memory recall was a real concern if I were to ask participants in an interview to describe how they felt about incidents of care across the last two weeks. The potential of the follow-up interview afforded me the opportunity to expand, probe and explore and to gain some clarity when entries were difficult to interpret.

Elliot (1997) describes the follow-up interview as a triangulation process between the researcher the participant and the diary, where inconsistencies can be checked, gaps can be filled in, and researcher misinterpretation can be avoided. Kenton (2010) warns however, that the interview should not be a means for the researcher to 'check-up' on whether the diarist has been honest, but to explore different perspectives. Kenton (2010) and Zimmerman and Wieder (1977) suggest that the interview gives the participant an opportunity to reflect on their entries and their experiences and to gain insight through discussion about their lives and how they are situated within them.

There may have been omissions in the diary, and I looked for possible gaps. For example, one participant seemed reluctant to record much detail about her relationship with one particular carer. I used the interview as way to gently probe into this. Zimmerman and Wieder (1977) discuss the use of different probing techniques including direct pre-prepared questions such as “could you tell me more about that” and non-directive probes for example ‘mm...mmmm’ or “you mean the world or what?” (p.490). I was acutely aware that I should be subtle in the way in which I explored such sensitive subjects as personal care.

Whist I made it clear in the diary instructions that should a participant feel uncomfortable writing about an issue, they could mark the page with an asterisk, interestingly, none of the participants marked the diary in this way. However, I discovered during some interviews that there were things that had happened that they had not felt comfortable even marking up for later discussion.

4.3 Ethical considerations

This study received ethical approval from the Anglian Ruskin University Faculty (of Health, Social Care & Education) Research Ethics Panel Faculty (FREP) in November 2013 (see Appendix 1)

Data was collected using the three mediums, by way of the recorded interview at the initial biographical-narrative stage, the use of the diary, and the final semi-structured interview stage. I had to consider very carefully how to manage confidentiality using these very different methods.

I was mindful that my research explores the sometimes sensitive subject of care and as such is “research which potentially poses a substantial threat to those who are or have been

involved in it” (Lee, 1993 p.4). Being aware that the process of conducting ethical research should, at the very least, cause no harm, I knew that anonymity was a principal concern. I promised to protect identity and maintain confidentiality of data. I gave this promise on the understanding that if a participant mentioned any harm to self or others I would be required to disclose this to authorities. I reassured them however, that I would first discuss this with the participant and then with my supervisors before agreeing any course of action.

In order to gain informed consent it is necessary for prospective participants to have sufficient, accessible information to enable them to make an autonomous decision to take part in the research (Wiles, et al., 2008). It must also be made clear throughout the research process that participants can withdraw without coercion and without negative repercussions. This is particularly important when research involves vulnerable people (Crow et al., 2006). Informed consent in this regard is an on-going collaborative process, allowing participants to negotiate and revise the original consent arrangement (Houghton et al., 2010). However, if a participant reports being the victim of a crime or if they are at risk of harm, the researcher may feel a moral responsibility to disclose information. In their study with social researchers, Wiles et al. (2008) found that most researchers felt a moral responsibility to disclose in some situations, particularly when working with vulnerable people, albeit with permission from the participant to do so. However, a dilemma arose when participants did not give permission for the risk of harm to be disclosed. Wiles et al. (2008) suggest that there is a conflict between paternalism and autonomy, with researchers wanting to protect participants on one hand and on the other hand granting the participant control over the use of information. Johnson and Clarke (2003) evidence, in their study with researchers, that making a decision not to disclose risk of harm can also leave the researcher feeling anxious whether, for the sake of the participants well-being, confidentiality should be breached. However, Sieber and Tolich (2013) warn that researchers should consider that ‘risk’ is subjective, with different groups of people having different perceptions of what constitutes risk.

After each of the interviews I transferred the recording to a password protected file on my password protected University laptop computer ready for transcription, being mindful of the need for confidentiality and data security (Leavy, 2014). I deleted the interview from the recording device as I was concerned it may be lost or stolen as I made my journeys to other participants. I then proceeded to transcribe the interviews, deleting any names, including those of participants, carers, care organisations, family members etc. replacing them with

anonymising codes. During communication via emails, letters or in creating personal logs of phone calls I used codes rather than participants' names. I devised a personal password protected database of names against allocated codes. I stored all manual files, paper copies of transcripts and consent forms in a locked cabinet. I ensured I had sole access to these documents and that they would be destroyed once the study was complete. I made each participant aware of this level of security in the PIS. However, I was also aware that during the interview, participants may be concerned about the consequences should anyone and in particular, a carer overhear, and that this may affect the relationship they have with the carer/care organisation and the care they receive. I reassured each participant that if I arrived to carry out the interview whilst a carer was still present, I would return another time at their convenience. This would mean that I was also avoiding intruding into what is sometimes a very personal care domain.

With regard to the confidentiality of the diary, there were two issues I was aware of. Firstly how secure the diary was within the participant's home and whether it could be read by others, and secondly, the type of information that participants felt comfortable writing in the diary.

With regard to where the participants stored the diary in their own homes, I felt that this would be very much down to their own discretion. Since some diary entries make reference to the actions of carers and how those actions affect their sense of self, I did make a point of asking participants whether they would like to keep it in place where it is private to themselves. Most participants were happy to keep it near them, knowing that others would not have access to it without their permission. I felt it would be inappropriate for me to request that the diary be kept under lock and key. This may have not only caused alarm but some participants were immobile, depending on the table next to them for keeping documents etc. at hand.

The other issue I was concerned was that participants may feel uncomfortable recording their thoughts and feelings about a sensitive subject or event associated with their care. They may be concerned that it might be read by a carer before I collected it or that writing about an incident might make what could be a disturbing event even more stressful.

With regard to gaining informed consent, it is a requirement of the FREP ethical guidelines that consent is received before involving individuals in the research. Once I had received

participants' contact details, I telephoned them to confirm their interest, to outline the study and how they would be involved and to make a date for my first visit. I explained that if they were happy at this stage to take part I would send to them a copy of the PIS and the PCF in the post. Since I was working with older people, I considered the fact that some may have failing eyesight, and so both the PIS and PCF were adjusted to a clear and large Ariel font size 14 and using clear accessible language. I explained that the information sheets would give them a chance to read about what was involved at their own pace and that they could contact me either by telephone, by post or by Email if they decided subsequently not to proceed. However, if they decided to continue I would read it with them at the first visit making sure they clearly understood what was involved. Only then, if they were happy, did I ask them to sign the PCF before commencing with the first interview. I made it very clear that even if they did provide their consent, they could withdraw from the study at any time and without giving any explanation.

I was very careful to ensure that I followed these steps and that consent was given in a fully informed manner, and that participants did not feel in any way coerced to take part and that their consent was freely given. I did not want participants to feel obligated to take part, perhaps believing that I was in any way connected to their care organisation and that in refusing to take part they may be jeopardising their own care. I provided reassurance that the research was in no way connected to the current service delivery. I was also aware that because some older people may be experiencing loneliness and isolation they may be eager to participate (Finch, 1993), and I was conscious that I did not want to exploit “yet another index of their powerlessness” (McRobbie, 1982, p.57). However, I was also concerned that I did not over-mollify participants in my consideration of ethical issues. As a researcher there is a danger of assuming power and control and yet participants may have very clear objectives and their own sense of agency. In fact, one participant is a member of many committees working for the improvement of older people's services and this research afforded her the opportunity to voice her concerns about her own position within the care dynamic and she found the articulation of her own care story extremely empowering

I made no promises at any stage that I could make things better for participants - my terms of engagement were such that I was performing research that makes no claim to being action research. I was extremely careful to ensure participants knew that my involvement would, in

all likelihood, have no bearing on the care they receive, and that I would not be in a position where I was able to change their circumstances to any significant degree.

I was also conscious all the way through the stages of data collection that talking about their personal history and/or circumstances surrounding their care may trigger emotional distress. I remained vigilant at all times, being sensitive to verbal and non-verbal signals of any kind of upset, checking all the time that they were happy to proceed. I was also ready to provide contact details of appropriate individuals and organisations for additional support, although this was never required.

Whilst they may have provided consent to take part, many participants have long term health conditions that may have meant taking part became more difficult as time progressed, particularly since it spanned a period of at least four to six weeks. I made sure at each stage that participants were physically and mentally well enough to proceed and again I remained sensitive during interviews to any signs of distress or fatigue, negotiating with participants about taking a break, postponing the interviews or withdrawing from the study altogether. I also ensured that I was familiar with any local emergency procedures should they become ill during my visit.

Similarly, attrition may be due to fatigue or boredom as participants lose interest over time. I was observant of any loss of interest during all stages of data collection, providing encouragement and support but reassuring participants that they could withdraw at any time with no penalty. I also checked before each visit that they were still happy to continue and for me to attend as arranged, thus giving them the opportunity to withdraw.

In the section on the diary presentation, I explored how there may be barriers that make diary completion difficult for some participants and how this calls for careful and sensitive management of whether this may exclude participants from the study. I was also aware that barriers may exist not just for the diary but for the general research process. At one day centre I was invited by the group leader to speak with one lady who might be able and willing to participate. It transpired that English was not her first language and my non-existent command of Polish and her limited command of English made it impossible for us to proceed. I gently explained to the lady that it would be difficult for us both to continue. This of course excluded from the study those from ethnic minority groups who were unable to communicate, verbally and in writing, using the English language.

4.4 Recruitment

4.4.1 Inclusion criteria

The inclusion criteria for the participants were:

- Men and women aged 65 and over
- In receipt of care in their own homes
- In receipt of a formal care package that is either privately or state funded or combination of both, and not delivered solely by friends or family
- Living in the Eastern region (or further afield as time progressed)
- Able to communicate both verbally and in writing using the English language

With regard to the type of care being received, I decided that care must be delivered by way of a formal contract, that is, not informally by friends or family. The dynamics of care and the way in which care interacts with identity was very different when delivered formally and by people not known to the participant (Moscovice, Davidson and McCaffrey, 1988, Pickard et al., 2000). With regard to the communication criteria, my research would potentially exclude those who were suffering from an intellectual impairment such as dementia, if it meant that reading and writing about even very recent events was too difficult. I remain concerned that I am unable to include this group of people, as I feel they are perhaps the ones for who retaining a sense of self is so important. Indeed Cook et al. (2009) posit that the meeting of psychosocial needs is at the centre of high quality care for people with dementia over and above meeting physical need. Wergeland et al. (2014) report that older people with dementia are at risk of being isolated and lonely and that they typically suffer from depression, anxiety, apathy and irritability. Hansen et al. (2017) suggests that the use of support groups, cognitive therapy, and reminiscence can enhance psychological and social health yet these opportunities may not be as readily available within the home care setting and that the focus is typically more on the psychosocial health and needs of family caregivers. Kitwood (1997) asserts that the home care of people with dementia should be flexible, person-centered and delivered in such a way that respects individuality. However, Miranda-Castillo et al. (2013) report that there is paucity of research into home care services for older people with dementia and that psychosocial need is prioritised at a lower level than physical need. During my time working as a domiciliary carer I cared for many people with dementia and one of the most valuable tools was a life story book that some families had written for carers to read. Gibson (2011) posits that triggers such as photographs, physical props and music can be

successful in stimulating memories. I certainly found the use of the life story book to be an excellent way of connecting the person being cared for with their past selves and provided a rich source of conversation allowing carers to explore with the older person their personal history and to illuminate sometimes hidden identities. Yet I knew that because of my research design, I could not include older people suffering from any kind of intellectual impairment. I see this as an opportunity for further research.

It was essential for participants to be able to hear, speak, read and write. Of course, if they were unable to write I did offer the use of a recording device as discussed earlier. Again I was disappointed as this group were the ones that I would like to represent in my research as they were potentially the ones who were most isolated due to their disability. Yet they remain hard to reach and I suggest this is a challenge for further research.

I knew that older people receiving care in their homes can potentially be hard to reach if they have limited mobility and fewer opportunities to engage with others. I knew that I had to be imaginative in my recruitment and it proved to be a challenge from the outset. I decided to focus my attention on Eastern England including Suffolk, Norfolk, Cambridgeshire and Essex although I knew that if I was unable to recruit locally I would be prepared to travel further, being mindful of the fact that data collection spans three visits and could be more expensive and time consuming the further I travelled.

4.4.2 Recruitment via different organisations

I contacted numerous charitable organisations by telephone and by E-mail asking for help with recruitment in promoting my research using their websites, magazines, and any other media that would reach this group of people. Age UK Essex, Age UK Suffolk and Age UK Cambridgeshire agreed to include an article in their quarterly magazines. Likewise, Independent Age publishes a national bi-annual magazine *Golden Link* and they also agreed to include my article. However, I received just two responses from older people via these publications. It is difficult to ascertain why the response was so poor since I cannot poll the group. I do know that older people do receive these magazines in the post, as I have seen them by chance when I have been to their homes to carry out interviews. I have also seen them displayed in Doctors' surgeries, hospital waiting rooms etc. but access to these areas may be limited due to mobility issues.

I also decided to approach day centres within the Eastern region, asking if I could attend a session and speak to older people directly about my research in the hope of recruiting participants. I attended four day centres and recruited thirteen participants. I also left fliers of my research with the day centre managers in the hope they may place them on information boards. Unfortunately many of the people who attend the day centres have dementia and are consequently excluded from the study. Similarly, many of the attendees were extremely hard of hearing or had limited vision and again were not be able to take part. Nevertheless this avenue proved to be most fruitful and I also made some very good contacts within the day centre circle.

I knew from my own care experience that there was a population of older people who did not attend day centres either because they were physically unable to do so or because they chose not to. It was this group of people that proved the hardest to reach and yet the group that I wanted to include within my research. They are perhaps the most isolated, the loneliest and potentially the ones who struggle to maintain their independence, autonomy and sense of self. I had to try to reach them in some way and so I approached two housing associations that provide sheltered housing to older people. I asked them if they would promote my research by way of their magazines and by placing the fliers in the common rooms. I was disappointed that there was no response using this source.

Whilst speaking with the charitable organisations, I asked whether there were any user groups or forums that I could attend and speak about my research in an attempt to recruit participants. I was invited along to speak at various forums. I attended a monthly group and managed to recruit two people via this channel. Whilst recruitment was slow, it did disseminate my research across communities and afforded me the opportunity to network with organisations and older people interested in care and to feel more in touch with how care is delivered and received at the grass roots.

Care organisations, by their very nature, have access to many thousands of older people receiving care at home, yet I decided not to approach them to ask for help. The focus of the research is not to evaluate the practice of care agencies but rather how care interacts with a person's sense of self, how it promote feelings of autonomy, independence and dignity and how being in receipt of care affects feelings about themselves. However, this would naturally include discussions by participants of care practices, carers and care organisations. I decided therefore that care organisations may be reluctant to take part and that if they did, they might

promote my research to only those older people with whom they had a positive relationship and possibly encourage, even coerce older people to provide a positive account of their experiences of care.

Qualitative research, due its very nature, does not call for a large number of participants, and I was not dissatisfied with the final total of seventeen participants. However, I was disappointed that I had failed to reach out to those older people who were isolated within their own homes, to hear their voice about their care and their selves. Engagement in research has benefits for older people and for organisations. Taylor (2010) suggests that engaging older people in research such as this, provides an understanding of older people's perspectives, challenges ageism and ensures research is relevant, important and has greater impact. Gough (2010) also highlights benefits for older people such as the opportunity to meet others and to increase feelings of empowerment, stimulation and interest. Yet there exists barriers that older people must overcome if they are to take part in research (Age U.K., 2011). Foot (2009) suggests that people may be reluctant to take part in research due to lack of confidence and skills. She goes on to submit that people might find processes and structures of an organisation confusing and challenging, and that the culture and language used by staff might seem strange to an older person. However, Age U.K. (2011) also mention physical visual, auditory and mobility challenges that present as barriers to participation, along with the timing of appointments potentially intruding on needed care visits. They also suggest that calling out for participants for a study into older people's services may be off-putting. Some older people may not see themselves as old and may not identify with activities that are aimed at older people.

When I did manage to engage with older people about the research, I explained the potential benefits of the study and endeavoured, where possible, to overcome through careful planning any physical barriers. However, I struggled to even speak to older people who did not respond to magazine advertisements, attend user group meetings or go along to day centres.

4.5 The sample- composition and demographic

Seventeen people have taken part in the research (see table 1)

Id	Gender	Age	Biographical-narrative	Diary	Follow up interview
1	Female	69	✓	✓	✓
2	Female	73	✓	✓	✓
3	Female	92	✓	X	X
4	Female	82	✓	X	✓
5	Female	85	✓	✓	✓
6	Female	72	✓	X	X
7	Male	86	✓	X	X
8	Female	67	✓	✓	✓
9	Female	82	✓	✓	✓
10	Female	71	✓	X	X
11	Female	67	✓	X	X
12	Female	92	✓	X	X
13	Female	92	✓	X	X
14	Female	90	✓	X	X
15	Male	74	✓	✓	✓
16	Male	82	✓	✓	✓
17	Female	90	✓	X	X

Table 1: The Sample

I recruited a total of seventeen participants to the study. I reflected on the sample size before, during and after recruitment and knew that the number of participants would be determined by both the research question and methodology and also “the style or theoretical underpinnings of the study” (Bryman, 2015, p.418). Qualitative research is often interested in more of a depth rather than breadth of understanding (Body and Boddy, 2016) and often involves studying cultures within specific communities (Trotter, 2012). Whilst I was interested in the objective circumstances surrounding their care, my primary interest was to gain a more subjective insight into participants’ perceptions and feelings about their selves within the home care dynamic. The biographical-narrative provided a medium to explore participants’ thoughts and feelings about being older and in a position of care. The diary allowed them to record incidents of care and to reflect on how care practices made them feel about their selves. Finally, the follow-up interview gave me the opportunity to further explore

these care practices against the backdrop of the narrative. I interviewed seventeen people and generated thirty three pieces of data that provided me with a rich and deep understanding of how care interacts with self within the home environment.

Of those seventeen participants, all but three were women. In spite of having made no mention of gender in any of the recruitment literature, I found it difficult to engage men to the study. At the day centre visits I spoke to men and women, but the ratio was on average 3:1 in favour of women attending the centres. Other studies with older people identify more women than men taking part in research. The Equality and Human Rights Commission report (2011) shows a 27:13 ratio in favour of women. In his home care study, Gethin-Jones' study reports a 23:17 ratio again in favour of women. He suggests this could mirror the gender proportion across the population with women typically living longer than men in the UK (ONS, 2010).

With regard to attrition, ten of the seventeen participants did not complete all three stages of data collection. My study spanned a period of approximately four to six weeks and attrition can often be attributed to the longitudinal nature of research (Barry, 2005). However, maintaining contact between visits can help to build rapport (Hermanowicz, 2013) and I contacted all participants between each of the stages providing them with reassurance and support, answering any questions, and reminding them of the voluntary nature of their involvement. In fact, for six of those ten participants who did not complete all stages of enquiry, the decision was made jointly following the initial interview. This was due to a combination of poor vision, limited reading/ writing skills and limited powers of memory recall. For example, Davina was very keen to take part and welcomed me into her home to complete the biographical-narrative interview. She understood the diary entry process and consented to take part but it was only at the very end of this visit that she confessed to being unable to read and write and had not read the PIS or the PCF. I then read her the contents of both sheets and asked her whether she would be happier using the recording device but she declined. Having sought her approval, the information she provided in the biographical-narrative interview was used as part of the final analysis.

I was not able to ascertain for one participant, Margaret, why she did not want to continue on from the initial interview. She was keen to take part and seemed to enjoy exploring her past during the biographical-narrative interview and was positive about the diary completion. However, when I contacted her to collect the diary she said that she had decided against it. When I asked her why she had changed her mind, she refused to comment. I did not pursue it

with her for fear of causing her stress and thanked her for her involvement, checking that she was happy for me to use the first interview as part of my research. Again the information she provided in the biographical-narrative interview will be used as part of my analysis.

Sadly, one participant Paul died before he was able to complete the diary. However, the biographical-narrative interview gave so much rich information about his personal history and his transition into being very much dependent on care, that, having sought approval from his widow, I included it within my final analysis.

Claire was extremely keen to take part in the research. She was immobile, and dependent on carers to hoist her from her chair for all activities, including toileting, bathing etc. She agreed to keep the diary next to her so that she could complete it during the day without having to ask for help. However, her carer removed it from her reach and refused to return it to her. Consequently she did not complete the diary. However, I did carry out the follow up interview exploring how she felt about the carer's actions and I will use both biographical-narrative and the follow up interview within my analysis as they are both rich in data.

Whilst ten of the seventeen participants did not complete all three stages of the enquiry, they did all complete the biographical-narrative interview as shown in Table 1. I decided to include their stories within the data analysis, since narrative is the cornerstone of this study. In fact, all of the biographical-narrative interviews yielded such rich data about how older people understand their personal journey into care and how they feel about their selves within their cared-for role that the study could have stopped at that point. However, I decided at the outset that the diary data of actual events of care and care practice would further enrich the data and the follow-up interview would allow further exploration and a deeper understanding and a coherence of themes that emerged in the earlier stages. I finally obtained thirty three pieces of data across participants and I treated them all equally in the analysis whether or not all stages had been completed.

Four of the seventeen participants, Lionel, Maurice, Paul and Susan, had their spouses with them throughout the data collection process. Whilst I tried to ensure that my visits were at a time when there were no visitors, and particularly when there were no carers present, it would not have been appropriate for me to ask spouses to leave since they were all very much involved in the care and support of their partners. They were an integral part of the care and knew and understood how their loved ones felt about the care they received and had appeared

to have some insight into how it affected their sense of self. Lionel's wife said very little, whilst Maurice's wife supported her husband's account, providing additional detail and information as needed. Paul was extremely ill at the first meeting and his wife did much of the talking on his behalf, with Paul nodding or shaking his head or adding small snippets when he was able. Susan's husband also did much of the speaking for his wife when she was too unwell to take part, although she listened and interjected when she disagreed with his account. For both Paul and Susan I was concerned that I was not hearing the direct voice and that I may be hearing the spouse's version of care and their thought on how it interacted with their partners self. However, I endeavoured throughout the interviews to engage as much as possible with Susan and Paul, looking for any verbal or non-verbal signs of disagreement. Susan's husband also wrote in the diary as her movement had become so limited she was unable to write. When I returned to carry out the follow-up interview, Susan was much more awake and able to participate and so I read her some of the diary entries, probing with her how she felt about the diarised care practices. Again her husband supported her but I was careful to address questions directly to Susan.

I reflected on the relationship between husband and wife. I considered the extent to which the spouses' statements represented participants' views. Whilst more objective consideration such as care routines and practices were more straightforward, I was careful to ensure, where possible, that when they made more subjective statements about their partner's thoughts and feelings that these were supported by the participant. I knew that, as a family, the relationship between these husbands and wives was a complex set of "individual personalities, a system of interpersonal relations, and local culture" (Handel and Whitchurch, 1994, p.4). I would not be able to understand, in such a short space of time, the way in which this family system operates and the nature of the relationship between husband and wife, and whether there were issues such as power, control, honesty and trust (Minuchin and Fishman, 1981). Furthermore, I would not be able to determine how such issues might affect the accounts that were given. However, knowing that the spouses' accounts were invaluable, I reflected both during and after each interview and engaged the participant as much as possible in the process, using verbal and non-verbal cues to check that they agreed with what was being said. Where I felt any comments were not representative I excluded these from the transcription and hence the analysis.

4.6 Data analysis

4.6.1 Transcribing the interviews

Transcribing is a time-consuming process with reports of one hour of speech taking at least three hours of typing (Bailey, 2008). However, in transcribing the text myself, I would be hearing the spoken word again, and become even more familiar with the content and perhaps pick up on nuances that I may have missed during the interview. I therefore decided not to outsource the transcribing process. Bird (2005) sees this transcription process as “a key phase of data analysis within interpretative qualitative methodology” (p.227). I did try passing a recording out to a third party but when I received the transcription back I felt disconnected from the source, and somehow remote from the text .

Secondly, I had to decide what level of complexity and detail the transcription should contain. Sandelowski (1994) acknowledges that transcribed text can never fully capture the complexity of the interaction, or be totally error free, and yet I knew that this could affect the reliability, validity and integrity of my analysis (Seale and Silverman, 1997, Easton, McComish and Greenberg, 2000). Seale and Silverman (1997) have recommended that the verbatim transcription of text should be accompanied by symbols and expressions that provide a naturalistic representation of the spoken word. Sandelowski (1994) suggests that this is not always necessary and it is the content itself that is most relevant. I knew that there were points during some interviews when participants had become distressed whilst recounting some of their experiences and yet this was not reflected in the written version. After each interview I updated my reflective journal, noting how the participant had felt during the interview. I also recorded my own thoughts and feelings about what had happened.

4.6.2 Organising and analysing the data

Gibbs (2008) describes qualitative data analysis as falling into two stages. Firstly organising the data by sorting, retrieving, indexing and handling what is often voluminous amount of data. Secondly, the process of reducing the data into themes and using interpretive skills to produce findings and develop conclusions.

With regard to data organisation, for each participant, I transcribed the interview and typed up the diary in preparation for the follow-up interview. I then began generating a list of initial codes or “the most basic segment, or element, of the raw data or information that can be

assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p.63) I was careful not to strip out surrounding rich contextualising text (Bryman, 2015), returning to the recordings, reminding myself of nuances and details that I may overlook.

I also knew that one piece of text may in fact fall into two codes and I was not concerned about repetition. I then read and re-read the data set making sure I had coded thoroughly. Initially I used a manual method, writing codes on to notes and sticking them on to a large piece of paper ready to organise them into themes. However, this quickly became unmanageable and so I imported the source data into NVivo and continued with the coding electronically. However, I was moving away from the text into a more logical almost remote view of my data that denied the richness and complexity of the narrative. At this early stage I did consider reverting to manually organising the data. However, with thirty three sources I decided this would be too big a challenge, so I persevered with NVivo.

I then moved on to the second stage - that of generating themes from the biographic narrative and diary codes (see figure 7). See Appendix 5A and 5B for the thematic analysis of Susan’s biographical-narrative and diary as an example.

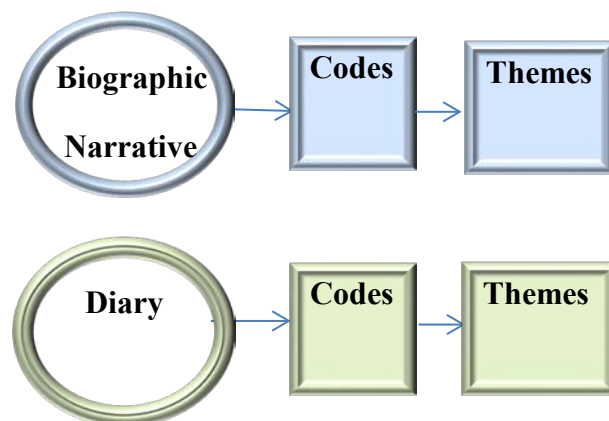


Figure 7: Analysis of the biographical-narrative and diary

This analysis stage progressed from the descriptive level to a more conceptual level of labelling (Bryman and Burgess, 2002). This process was very much inductive in that, even though I had completed the first draft of my literature review, I felt that the analysis should not be determined by my theoretical interest. I endeavoured to divorce myself from any preconceptions I had about the subject of care and identity. However, I was aware that I could not remove myself completely from the process. My sub-conscious thinking affected the

choices that I made in the codes that I selected and the themes I generated and that there is a “two-way dialectical process or ‘flip-flop’ between data and the researcher’s conceptualisations” (Schiellerup, 2008, p.169). Whilst I was keen for concepts to emerge from the data rather than be deductively influenced by literature, I reminded myself of the research questions bringing me back to the purpose of the enquiry (Dey, 1993) After a short time of assigning pieces of texts to nodes however, the number of nodes grew rapidly and I needed a framework on which I could build my analysis. I returned to the literature review and looked at the care/identity/ageing structure and the theories embedded within. I returned to NVivo and crafted a node structure that mirrored my literature review framework and resumed the coding of sources. Yet it soon became apparent that I would not be able to neatly assign pieces of text to the theories I had explored through my review of literature to date. Other issues were discovered and different perspectives were emerging, and the inductive nature of the study became apparent. As I began to look for emerging themes across sources and nodes, I felt that I that I was trying to fit rich, diverse, and very individual stories, into a logical representation of the data. As Anfara (2006) warns - a theoretical framework may be too reductionist and the researcher may fall into the trap of trying to ‘fit’ the data into predetermined categories. Consequently, my node structure evolved, moving away from the rigidity of the theoretical framework into a richer more empirical representation.

At this stage of analysis I was also concerned that that with my increasing dependence on technology, spending several weeks mastering NVivo and coding data, it was essential I did not allow myself to become detached from the participants. Crabtree and Miller (1999) suggest that there are three different aspects of qualitative data analysis. They describe a dance between a literal, an interpretive and a reflexive understanding of the text. I felt that in absorbing myself entirely in NVivo coding of text, my analysis was becoming too literal and the text was beginning to lead the dance. Hence I decided to give myself some space from NVivo, and with hardcopies of the sources, and with my reflexive diary I gave myself some thinking time, just looking at the data to see what it revealed to me. I also wanted to revisit the participants through their stories, so I listened again to the transcripts and constructed a vignette for each participant (see Appendix 6). This period was fruitful. I began seeing themes across participants, themes that emerged not from the text alone but from looking across the data and listening to the voices that were both dominant and silenced, what participants were telling me and what were they avoiding. I moved iteratively backwards and forwards across the data sets, further defining and refining the themes and rechecking the

data within them and identifying where there are large themes and any hierarchical sub-themes. At this point I was able to describe the themes that I had generated across all sources and understood their essence. To promote validity of the analysis at this point, I asked my supervisors to check my coding and themes across a selection of participants to confirm that they were able to flow my logic and draw similar conclusions (Cresswell, 2012).

Once I had completed this thematic analysis I was then ready to prepare a list of probes and questions for the follow-up interview based on the generated themes (see figure 8).

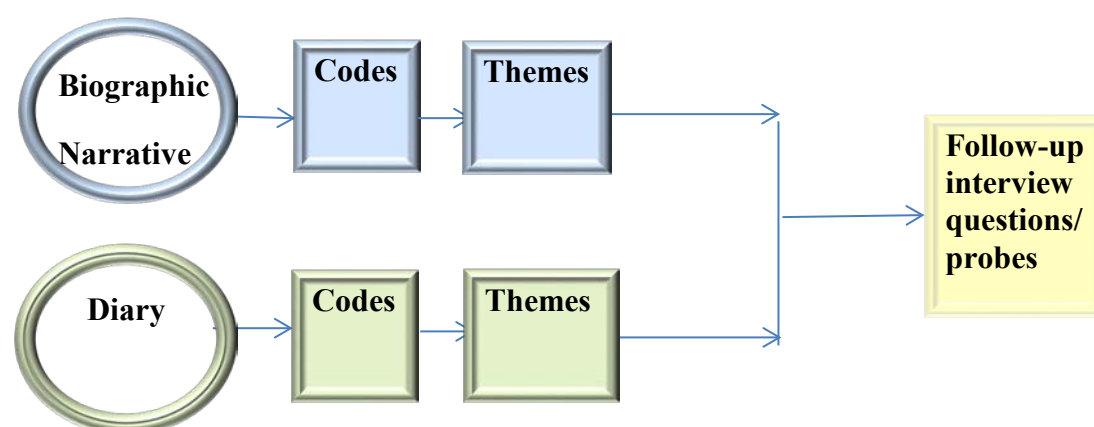


Figure 8: Analysis of the biographical-narrative and diary: Generating codes and themes and the questions/probes for the follow-up Interview

For example, the analysis of Maurice's biographical-narrative generated themes of *earlier life endurance* and *positivity*, as he spoke about the importance of the friendliness of carers during his life-long struggles with disability and how they had contributed to his positivity and endurance. The thematic analysis of his diary generated a theme of *regularity of carer* as he spoke about the value of the familiarity he developed with his current regular carers. I used these themes to generate a probe in the follow up interview, in order to understand how having regular carers interacts with his sense of self, and his positivity in the light of the difficulties he now faced.

FOLLOW UP IV PROBE: *I just want to reflect with you, as I weave through the diary, it comes back to the things we talked about in the previous interview, and what came out in the previous interview was the importance for you of the friendliness of the care that you have received through your life. Having already looked through the diary you're saying things like 'lovely chat', 'talking about grandchildren – hers and ours'.*

Similarly, the thematic analysis of Lionel's biographical-narrative generated a theme of *earlier life dependability* as he spoke about the careful way he had previously managed his life, placing great importance on punctuality and reliability. The thematic analysis of his diary generated a theme of *timings of carers' visits* as he spoke about how frustrated and disappointed he felt when carers were late with no prior notice. I used these themes to generate a probe in the follow up interview in order to understand how lateness of calls affected Lionel's sense of self and his need for control and punctuality.

FOLLOW UP IV PROBE: *Going back to the first interview what you talked about was regular times and regular people and that was really important to you. In the diary though you wrote about carers being late. ...*

After the follow-up interview, I transcribed the data and using NVivo (Bazeley, 2013) I created codes and generated themes as before (see Appendix 5C for the thematic analysis of the follow-up interview to complete the full data set for Susan as the example).

I now had a complete single data set for each participant with codes and themes from the biographical narrative, the diary and the follow-up interview. (See Figure 9)

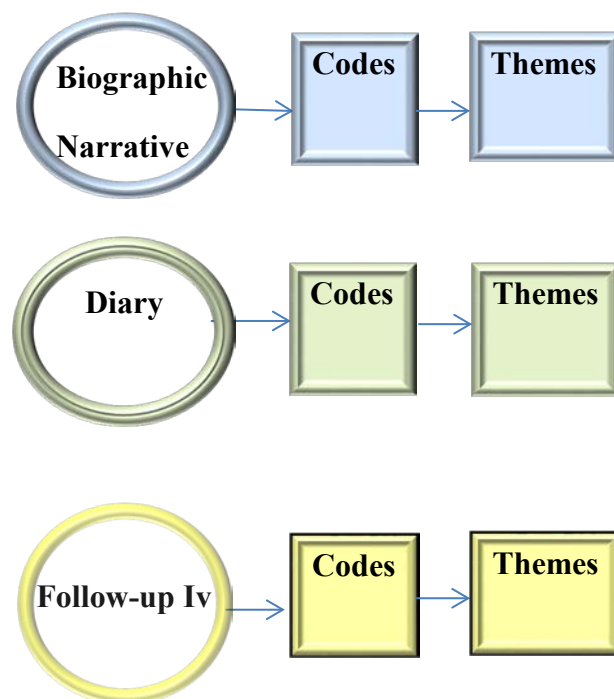


Figure 9: A complete data set with codes and themes

Once I had completed all of the biographical narrative interviews, collected all the diaries, carried out the follow-up interviews and the subsequent coding and thematic analysis, I was ready to write the narrative of my findings, using the themes, along with carefully chosen supportive extracts from the texts. At this stage I theoretically connected the themes back to the literature review (Dey, 1993) and related it to the work of other researchers in order to establish theory.

4.7 Researcher positionality

I found it a challenge at each of the data collection stages to remain within the role of researcher. Having worked directly with older people within the domiciliary care setting along with being a qualified social worker, I was aware of the extent of the difficulties that some older people experience within this setting. I had to be very careful that my open questioning was about the participant's view of their world, their selves and their lives (Holloway and Wheeler, 2013) and not based on my assumptions drawn from my own experiences. The very nature of qualitative research means that the researcher is working at a subjective level, and preconceptions can influence the way in which data is gathered, interpreted and analysed (Starks and Trinidad, 2007). Bracketing according to Drew (2004) is a way of "sorting out the qualities that belong to the researcher's experience of the phenomenon" (p. 215). However, some claim it is impossible to bracket yourself even after going through a process of identifying your own beliefs, assumptions, values, interests, emotions and theories and attempting to set them aside (Slotnick and Janesick, 2011, Leavy, 2014). Yet as Leavy (2014) suggests, it is possible to take a balanced approach and I acknowledged my experiences and preconceptions and recognised how as a researcher I impact on how the data is managed. The reflexive journal (Ahern, 1999) and memos (Cutcliffe, 2003) are a way of identifying and managing thoughts and feelings throughout the research process. Many times, when I left a participant, I was left with some strong emotions and I used these tools to record and reflect on how they were affecting me and ultimately how they may impact on the next stage of gathering data. Rarely did I interview two people on the same day and so I had time to reflect, process and release feelings.

I also had to remind some participants that whilst I was a qualified social worker and that I had exposure to care agencies in the recent past, I was not able to answer any questions about their care package. At times this was extremely difficult for me to leave alone, as I felt that I may be able to help in some way and I felt a strong need to 'fix' things that I felt were wrong.

Allmark et al. (2009) warn that researchers can often take on a dual role as researcher and of therapist, with a strong need to intervene, and that this is particularly relevant when interviewing vulnerable people. However, I knew that my remit was as a researcher and I endeavoured to remain within that role.

It is acknowledged across literature (Creswell 1998, Silverman 1998) that both participant and researcher influence and learn from each other, thus potentially influencing the research outcomes. During my time as a carer I became interested in the way in which an older person's sense of self could be so affected by the way in which care was delivered and it was this interest that led me to this research. Equally I believe my current role as a doctoral student at a university gave me some degree of credibility when I spoke with professionals across agencies, and has perhaps opened some doors for me. Furthermore, my academic status was recognised by some participants who were extremely interested in the research process, providing a topic of conversation and a means of creating a more relaxed environment. There have been times though when I have struggled with my research and I have felt fraudulent in this exalted role, although the use of my reflective journal has helped me to process these feelings and to refer to them in supervision if needed.

4.8 Trustworthiness of qualitative data

As opposed to its quantitative counterpart, the qualitative methodology seeks not aggregate evidence or objective truths, but contextual and subjective depth and breadth in the experiences of life (Ambert, Adler, Adler, and Detzner, 1995). Qualitative research does not seek to generalise data to the population, but recognises that a phenomenon must be explored in a holistic manner and is more than the sum of its parts (Leavy, 2014). The quantitative paradigm is based on positivism, where, from an ontological perspective, phenomenon can be reduced to one truth. The qualitative paradigm on the other hand, is constructionist, interpretive and takes an ontological perspective that there is not one truth, but multiple and evolving realities, and an ontological position that there are no external realities against which any truth can be measured, since the reality is contextually created.

In the naturalistic context of qualitative research, the concepts of validity and reliability cannot be addressed in the same way as they would be in a quantitative study and positivists frequently question the trustworthiness of qualitative research. However, authors, notably

Silverman (1998), Lincoln (1985) and Guba and Lincoln (1989) have proposed criteria by which the trustworthiness can be established.

I incorporated a combination of these criteria into my research in my endeavour to reach trustworthy status and considered the two areas of validity/credibility and reliability/dependability.

With regard to validity and credibility, these two terms seem to be used interchangeably across literature, however, credibility seems to me to be more related to a qualitative paradigm and one that I will use. Guba and Lincoln (196.1.389) suggest that the term validity suggests measurement and belongs in the absolute and positivist camp.

Credibility refers to truthfulness and the transferability of findings. With regard to truthfulness, I have employed three methods of collecting data, the biographical-narrative enquiry, the diary and the follow-up interview. I have also used my own reflective journal. I employed a circular and iterative process of reading and re-reading the transcripts, listening to the recordings and referring to my own notes. A more exhaustive check would have been to invite the participants to read the transcripts and the themes to check for consistency, and as another method of promoting truthfulness (Koch, 1996). Clayton and Thorne (2000) devised a system (DAViT) for enhancing the rigour in diary that they presented to participants when analysis was complete and it was something that I considered. However, it would have involved returning for a fourth time to the participants asking them to check the data. I decided that three visits were enough for older people, and that it would place them under further stress.

To ensure that the data collected within this qualitative research study was correctly interpreted (Lincoln & Guba, 1985) and in order to increase credibility, I invited my supervisors to review the coding and the thematic analysis from randomly selected data sets.

At the very start of my analysis, I provided them with some text segments asking them to identify the codes within that piece. I then compared their coding with my own and discussed with them the differences, learning where I may have misinterpreted the data. I then repeated the exercise as I moved further into the analysis and the number of differences had reduced.

Once I had generated all the codes, I then looked for emerging themes. Again at the start of this process I presented my supervisors with a biographical-narrative and the codes I had

generated for that piece of data and asked them to develop themes. I then compared my own themes with those of my supervisors, learning from differences before moving on through the analysis of further scripts.

To ensure I was transparent in the way in which I analyse the data I was conscious of the need for critical reflection and hence the use of the reflective journal (Guba and Lincoln, 1989). I came to the study with a background in domiciliary care and my experiences have without doubt led me to this study. I have made this subjective position open from the start, and have been honest with myself and the reader about my pre-understandings and how they may affect the way in which I interpret the data. I have found a need to refer back to my reflective journal as I have met with more participants. Whilst I know I cannot remove myself and my thoughts and feelings from the study, I continue to reflect on my beliefs and assumptions as much as possible making best use of the reflective journal.

Koch suggests that transferability relates to what quantitative researchers refer to as external validity. Guba and Lincoln (1989) refer to this as ‘fittingness’, where the reader is able to take findings out of the context of the research, and apply them to their own experiences. The sample size of the research is relatively small (17) and as with many qualitative studies, it is difficult to apply findings easily to other settings. However, I will ensure that the way in which the thematic analysis was executed is transparent, and that the descriptions of findings are thorough. This will allow the reader to look for contextual similarities and assess whether they may be applicable to other contexts and thus be transferred.

Guba and Lincoln (1989) suggest that reliability refers more to measurement and belongs in the absolute and positivist camp and is less relevant to qualitative research. I will use the term dependability which refers to the accuracy and replicability of the data.

With regard to accuracy, errors in the data can compromise findings (Morse et al., 2008) and errors may occur at both the data collection and data analysis stages. Having three methods of data collection means that there is a greater chance of finding errors in the data. For example, whilst reading the diary if I noted any inconsistency with the biographical-narrative, I could explore it in the follow-up interview. I also expected that data collected across all three domains would converge at some point in the analysis. I also ensured my analysis of the data was extremely thorough, well organised and transparent and in using NVivo, I can offer colleagues the opportunity to examine the codes and themes for consistency and accuracy.

With regard to replicability, Koch (1996) recommends that, whilst another researcher may not reach an identical interpretation of the data or even collect the same data, they should be able to follow the decision trail, follow the logic and be persuaded by the conclusion. I developed a clear strategy for the analysis of the data, making it clear how the three methods interact and how I will apply the themes across the complete data set. Likewise, I have set out clearly my theoretical, methodological and analytical choices in an attempt to provide the reader with an opportunity, should they so wish, to take the data and follow the audit trail to understand how I reached the conclusion.

Chapter 5

Findings

The purpose of this research has been to gain insight into the lived experience of older people receiving care at home and in order to understand how care interacts with their sense of self. In this chapter I present the findings of my enquiry. I include a description of the setting in which the interviews took place and introduce the participants to the reader, before presenting the main themes that emerged.

I conducted the narrative interviews, the diary completion and the follow-up interviews in Suffolk, Essex and Cambridgeshire during 2014. Whilst I initially met most of the participants at day centres, I agreed to meet with them at their homes to introduce the study and gain their consent. This meant that conversations were private and they were in the comfort of the participants' own homes. This also allowed me the opportunity to contextualise their environment of care and to start to build a rapport with participants. All interviews were carried out in their lounge except for one participant, later referred to as Paul, who was too poorly to leave his bed. Partners and family members were sometimes in attendance and provided support. Interviews were carried out between care visits so that participants could speak freely about their care without feeling anxious that the carer may overhear. Furthermore, this preserved dignity when care was often of a personal nature. After introducing the diaries I left them by the participant's side leaving it up to them where they would be stored during completion

I interviewed seventeen people in total, with all but three being women (see Appendix 6 for vignettes for all participants). They were aged between 67 and 92 and all received formal care in their own homes. After carrying out the seventeen biographical-narrative interviews, seven of the seventeen participants went on to complete the diary and eight of the seventeen participated in the follow-up interview. They had a range of disabilities with varying degrees of severity and limited mobility. At the extreme, Paul could not leave his bed, yet Pauline was perfectly able to take care of her personal needs, walk a short distance to the local shops, but needed support at home with physically challenging tasks.

I gathered data using the biographical-narrative, the diary and the follow-up interview. Whilst each stage proved to be illuminating in its own right, together the methods provided me with

answers to my questions. Through the biographical-narrative I gained insight into how each participant had managed the stages of life, including now that they are receiving care, and also how they viewed their selves as they look back on their lives (Wengraf and Chamberlayne, 2006). Through the diary, on the other hand, I could see how they felt about actual incidents of care (Elliot, 1997).

Before carrying out each follow-up interview I analysed the biographical-narrative and the diary data. In this way I could draw on personal history and development of self, and link this to their diarised accounts of care in order to gain an understanding of how care practices interact with self and promote feelings of dignity and autonomy (see figure 10)

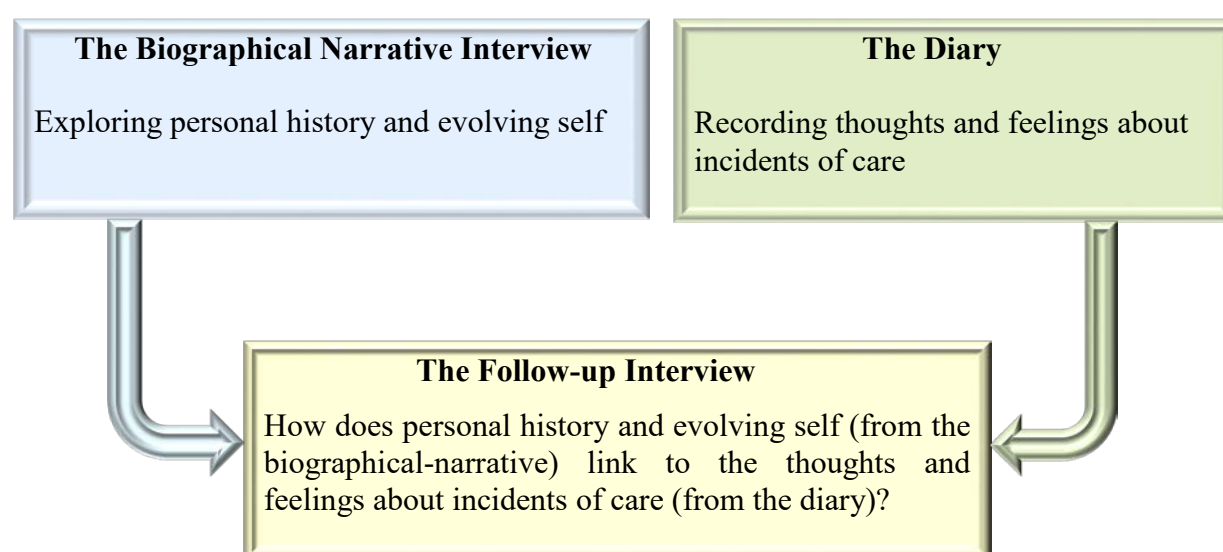


Figure 10: Interaction between the three stages of data collection

With regard to the analysis of data, I explain in the methodology chapter how, for each participant, I analysed the biographical-narrative and the diary in preparation for the follow-up interview. I also explain that not all participants completed all three stages of the data collection process, with nine participants completing only the biographical-narrative stage of the enquiry (see Table 1, The Sample). However, as I report earlier, each piece of data was treated equally. Data from the biographical-narrative was important in its own right since narrative is the fundamental, key element of this study, and could have stood alone in its richness. My decision, at the outset, to extend the enquiry into the diary and the follow-up interview stages was to enrich the data further and to grant the themes springing from the biographical-narrative greater coherence and deeper understanding.

I created codes and developed themes, inviting my supervisors to review the coding and the thematic analysis from randomly selected data sets to increase credibility. Boyatzis (1998) describes this inductive stage of analysis as recognising and coding important moments in the data, capturing its qualitative richness. However, very quickly the number of NVivo codes and themes grew unmanageable and I turned to the literature review, aligned with the research questions, to create a template of nodes. This template would serve as a data management tool to support the organization of segments of text (Crabtree & Miller, 1999). Fereday and Muir-Cochrane (2006) describe this as a “hybrid approach of inductive and deductive coding and theme development” (p.80).

The template resembled the format of the review with self/ageing/care forming the main themes, with sub-themes reflecting nested theories. However, as Anfara warns (2006) in trying to ‘fit’ the data into the template, the analysis may become too reductionist, and so my analysis at this stage was guided, and not confined by the NVivo node template. Indeed, some inductive codes did not fit into the template, as my initial literature review had not uncovered some themes. For example, in my initial search of the literature I had not considered the theme of ‘voicing concerns about care’ and how some older people were reluctant to raise concerns about the care they received. Yet my data revealed this as a theme and I extended the template accordingly. Similarly, whilst I discussed autonomy in the literature review, it became a far more significant issue across the interviews and the diaries, and it emerged as a strong over-arching theme in its own right. Thus my node structure evolved, moving away from the rigidity of the theoretical framework into a richer more empirical representation. My theoretical understanding and interpretation of the themes that emerged from the findings went beyond those that developed through the literature review. Consequently in reporting the findings in this chapter I wanted to highlight the contribution that my literature review had made to my analysis of the data, alongside engaging with the themes which emerged inductively and had not been a strong focus of the initial review. Accordingly, I have highlighted some of the links to relevant literature and theoretical approaches that arise from my findings in order to foreground the most pertinent issues in my discussion in chapter 6.

Four general themes emerged from the data:

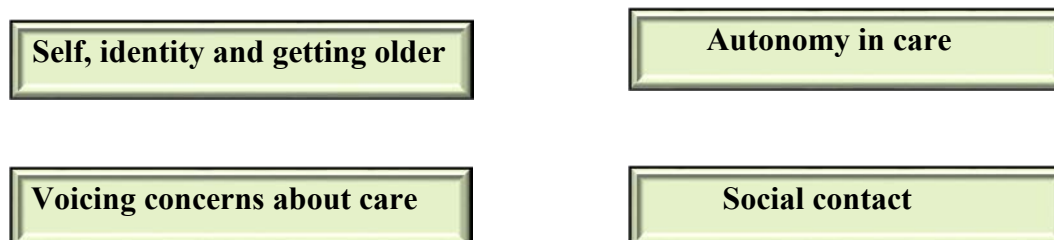


Figure 11: Four themes emerging from the findings

This chapter focuses on the themes and sub-themes that emerged. I will include extracts from the transcripts to retain the richness, depth and intensity that convey the life world of the participants. I include extracts that represent the issue being raised, and indicate, through my narrative, the number of participants that express this view. To maintain confidentiality and anonymity, fictitious names were assigned to each of the participants. Names were chosen at random that have no relationship to the persons they represent. Assigning names rather than codes would give a sense of the persons in the experiences (Given, 2015).

5.1 Self, identity and getting older

At the heart of this research is the notion of self and identity and how older people receiving care at home see themselves within the context of care. The narrative proved particularly fruitful in providing some rich data relating to sense of self, ageing and how the home space is affected in the care setting. Opening the narrative enquiry with the question “How have things changed for you since you have got older?” encouraged participants to express and explore their thoughts and feelings about how they have negotiated the later stages of their lives. They spoke about how earlier life experiences help to support them now, how they feel about ageing and how they adapt to the decline in their physical well-being. They also talked about the meaning they place on their home and the ways in which home has been redefined not only by the presence of carers, but also by the level of supportive equipment now occupying their home space.

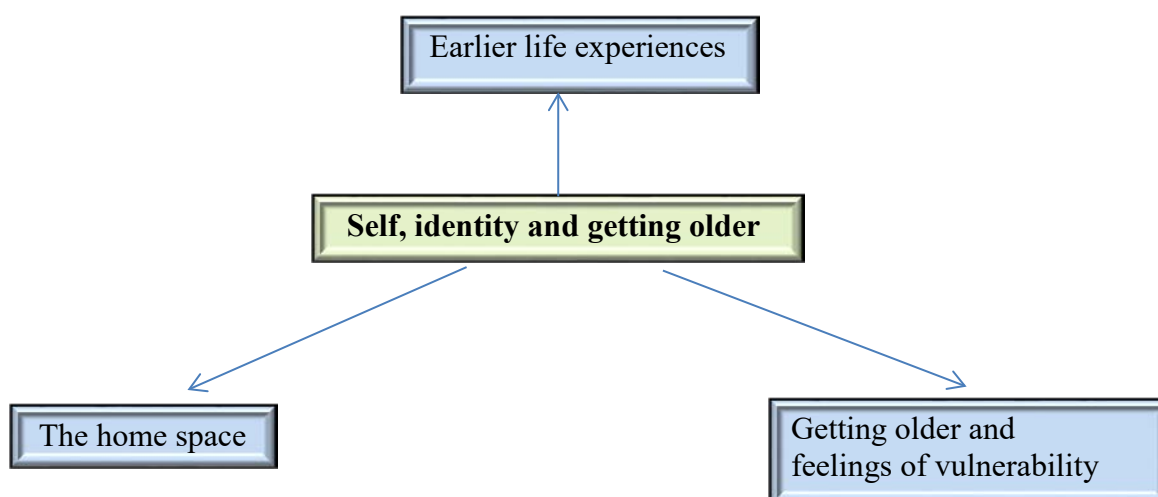


Figure 12: Self, identity and getting older and sub-themes

5.1.1 Personal values, earlier life experiences and strengths

In the literature review I explored whether there is an enduring pre-determined self that develops through the life course or whether identity is something that is socially and personally constructed along the way through roles that are enacted. My position supports both the life stage theory and constructionist theory. Whilst a person's biography exists and must be discovered and unfolded as it moves through the eight stages of psychosocial development, it is the social context that reinforces characteristics and provides stability of self. I found these concepts reflected in my participants' accounts.

Participants' accounts support Erikson's theory (1982) that growth and strength emerges from the battles of earlier stages of life. They speak of earlier life experiences that seem to have equipped them with perseverance and endurance to help them overcome the difficulties they now faced in a position of care. Maurice had to manage severe disability since being a teenager and he had always been determined to live a full life and present himself to the world as smart, able and positive. The coping mechanisms he had learnt throughout his life now served him well as he managed his increasing physical disability. Managing the challenging transition from being able-bodied as a young child to being severely disabled as a teenager, and then adapting to adult working life, marriage and parenthood had equipped him with values and skills that supported him in the cared-for role. His extreme physical limitations meant that he needed carers four times a day to help him wash, dress and go to the toilet. Yet he was determined to maintain his very high standards of presentation. His

personal appearance had always meant so much to him and he refused to let his standards slip in any way. When his wife commented on how Maurice had always been so fastidiously clean and always liked to wear smart clothes Maurice replied:

Maurice: *At one time I wouldn't ever go out without a tie on I don't like to give an appearance where I'm all dishevelled... you don't have to go round in stained clothes*
[Source: Follow-up Interview]

Even when he had a bad fall and was covered in bruises and obviously in a great deal of discomfort, when I arrived he was again well presented and retained his positivity and determination to overcome this challenging episode.

It is this sense of survival against great challenge that is also evident in the account that Violet gave. She told of how she has been widowed four times, had several children and managed her later life blindness with resilience and positivity. Similarly, Eva, 92, recalled how as a young lady she had to fight against shyness and a lack of confidence to achieve independence. Even after a nasty fall, the independence she had strived for in her earlier years served her well and she remained determined to get herself to the day centre:

Eva: *I had to be tough with myself since I've been having these falls but since then I've had to look at myself and say 'come on keep going....firm with myself*
[Source: Biographical-Narrative]

Clare demonstrated how she took great pride in the determination of her younger years when her family clearly struggled financially and later when she was diagnosed with multiple sclerosis:

Clare: *..and my doctor says I do admire you, lots of people would be bed ridden by now he said, I admire the way you walk and get out I think you're marvellous... You carried on all this time.. lots of people be buried by now... It's the way you're brought up, well think yourself lucky you even have a pair of shoes, never mind that the laces are broken. I thought well I got to get on with it if I'm going to go anywhere or do anything, so I go out three days a week*
[Source: Biographical-Narrative]

In recounting this story, Clare seemed proud of how she had survived the challenges of her childhood and believed this had equipped her with strength of character that supports her now

that she is disabled. She also seems to take satisfaction in the fact that her GP praises her spirit of survival.

It appears that each of these participants took pride in their determination to overcome difficulties in earlier years and used this fortitude to help them to manage their current situation. Erikson (1982) would suggest that they had successfully negotiated earlier life stages and that this was helping them to reach a position of ego integrity over despair as they move through the 8th stage of life. However, not all participants were able to view their current circumstances with such forbearance. Susan was once very gregarious and confident, yet now she slept most of the day due to the high level of morphine she took to manage her back pain. She spent the majority of the last few years in her chair in the lounge rarely going out of the house. When I asked how she felt about the change in her demeanour, her husband reported that she had always been a bubbly person with lots of energy, but she has now become reclusive, frightened of other people and very unsure of herself. Susan added:

Susan: *I resent it sometimes, I do resent it*
 [Source: Biographical-Narrative]

As I mention in my review, Erikson's work has been criticised for taking an ableness position in that there is little focus on how the life course progresses for those with disabling conditions. Reaching a position of ego integrity during the 8th stage of life means that the older person can reflect on their life's journey with acceptance and satisfaction. If they are unable to do this then they feel despair. Yet for Susan attaining ego integrity was challenging when she was in great pain and struggling with isolation and loss of autonomy and dignity. Furthermore, she was unable to realise her outgoing, bubbly self not only because of her extreme pain but also because she had little opportunity to express such characteristics within social contexts. She was self-conscious of how others saw her and felt that others defined her by her condition alone.

Similarly, Paul who had been confined to bed for many months due to a back injury also struggled to reconcile the change in his circumstances. He had once been a renowned entrepreneur yet now he was confined to his bed, isolated from society. When I asked how he felt about getting older and receiving care at home, his wife responded saying that he had retired into himself and even though he is still able to communicate his feelings, he is reticent in acknowledging his current situation as if he is blocking it out.

Like Susan, it seemed that Paul was feeling despair. It seemed that his pain meant that he was unable to reflect on his life and feel a sense of satisfaction and acceptance. His social world had disappeared and he was no longer able to realise those characteristics of himself that had supported his successful earlier life. He seemed unable to reach a position of ego integrity.

Whilst it was difficult to establish how successfully Susan and Paul had negotiated earlier life stages, their partners spoke positively about their level of happiness and life satisfaction before they became ill and needed care at home. Yet it was clear to see that their pain and their isolation was affecting their sense of self.

For Lionel, the reasons for his frustration and unhappiness were not pain and isolation. Rather his personal standards that he had held through his life were being threatened by the care he received. He had previously held a position of responsibility and took great pride in his professionalism and integrity. He placed great importance on reliability, honesty and open communication. These values remained very dear to him and he expected others to treat him as he would treat them. Yet he felt frustrated and unhappy when that care threatened his personal values and standards:

Lionel: *The care company I used to have would often be very late or not turn up at all. This would leave me feeling very angry, stranded, and insignificant. I am a creature of habit and feel more comfortable when things are done at a regular time. When we ring the office to discuss a time or a particular carer, the office say they will call us back but then they never do. We feel like we are just a number and then it also keeps us waiting around for a call that is not going to happen.... See I spent a lot of my working life in sales and if I couldn't fulfil something I said I'd do I'd ring the person up and not leave them to find out, which to me is courtesy. Hmm, it makes you feel like you're a number*
[Source: Follow-up Interview]

He was frustrated more by the fact that he had not been told, than by the effect the lateness had on his care. Furthermore, the fact that the office did not return his calls made him feel disregarded and unimportant. His expectations of how people should behave when dealing with others caused him a great deal of frustration. His sense of duty had persevered through his life, and showed no sign of waning as he moved from his professional role to that of being cared for.

These enduring values affected his experience of care enormously, and he felt unimportant and forgotten when the agency did not hold these values when delivering care. His strong need for honesty and clarity left him feeling ‘like a number’ when he was let down by care organisations.

Lionel demonstrated a high degree of satisfaction as he reflected on his life, taking great pride in his family and his career achievements. Yet he remained frustrated and unhappy. He had lost many aspects of his role within his family being unable to take care of others now that he was disabled. He had also lost his successful career role as manager and now he was in the role as cared-for. Stryker (1968) suggests that identity is socially constructed through the roles that are played out, with each role bringing forth a role identity and that we attribute meaning to ourselves through the roles that are enacted. Lionel was unhappy in his role as being cared for, feeling as though he had lost control over his personal world. Furthermore, he found the cared for role challenging when others engaged in that role including carers and care organisations demonstrated characteristics that he found unacceptable Swan and Bosson (2010) suggest that social contexts reinforce characteristics and provide stability of self, yet in Lionel’s case characteristics of reliability, integrity and honesty are not being respected. His determination to uphold these values led to him feeling unhappy and vulnerable when the care organisation did not demonstrate those same values.

5.1.2 Getting older and feelings of vulnerability

It seemed that for many participants their earlier life experiences had equipped them with characteristics such as resilience and determination that were helping them to manage the struggles of this later stage. However, I was interested in exploring with participants how they feel about growing older and how they feel other people’s attitudes towards them, particularly those people that come into their homes to deliver care, are influenced by the physical and emotional changes that take place in later years. I was also interested in finding out whether changes to personal, physical and cognitive attributes might make it difficult for one to feel that one is still the same person and whether this impacts on resolution of the integrity vs. despair conflict in the 8th stage.

Determination to resist ageing emerged as a powerful theme across the interviews. Many participants aimed to carry on doing things they always had, in spite of feelings of anger, vulnerability, hopelessness and fear for the future. Some struggled in many ways to see

themselves as older, yet in other ways they accepted the limitations and even at times felt defeated by them. They made use of adaptive aids, yet there was also evidence of other imaginative and inventive ways in which people tried to carry on, in spite of the restrictions caused by the ageing process. The positivity in the light of adversity was inspiring and humbling, whilst at the same time saddening to see the challenges that some faced and their fears and vulnerabilities.

Vulnerability was a major theme across the narratives, the diaries and the follow-up interviews, with ten of the seventeen expressing a fear of falling, with mobility being a major concern. Maurice's wife told of his physical vulnerability and how just walking from the car to his back door, even with the support of his frame, the wind had blown him over. Sadly he had laid there in the garden for more than an hour waiting for the medics to arrive.

Susan's husband told of how her ability to walk was declining, even with support from others and with the use of a stick. He explained how she is losing her strength and she nearly fell when being helped out of her chair, yet nothing can be done to improve her situation.

It is these kinds of events that lead some participants to be extremely cautious and to change their daily habits to reduce the risk of falling and to limit the damage if they did fall. Davina explained she could not let her carer help her in the shower as she felt he would not be strong enough to support her. Consequently she saved having a shower until her weekly trip to the day centre where she felt more confident that if she did fall, she would get help. Maurice had learned to adapt the position he took when he put his trousers on. He made sure that if he did fall it would be into the chair and not onto the ground. Davina liked to go into the garden but could not move around without using her wheelchair. Unfortunately the wheelchair ramp meant that whilst she could get outside into the garden, it was too steep to allow her to get back up to return inside which left her feeling isolated and desperate:

Davina: *I just say I hate my life... the loneliness*
 [Source: Biographical-Narrative]

Violet had several falls and in fear of another one she remained in bed in the morning until the carers arrived, obviously making her more dependent on the times at which carers called. On the other hand, Susan was taken to the toilet by the carer and yet because she was afraid of falling she had to wait on the seat until either the carer returned or her husband heard of her plight, which she feared could stretch into many hours:

Susan: *I couldn't get up, I was just dumped there, I thought I might be there hours because sometimes my husband, his ears get blocked and he can't hear me*
[Source: Follow-up Interview]

For Susan this vulnerability affected her dignity and autonomy further adding to her feelings of despair and unhappiness. She was once independent and capable, yet now for fear of falling she would suffer the indignity of being left stranded on the toilet without immediate help. Likewise Clare's fear of falling meant that getting older and being disabled affected her sense of self. She lived alone and could not walk at all, and the carers used a hoist to get her into a wheelchair whenever she needed to move around her home. Furthermore, her physical limitations meant that she had to use a catheter for urination and wore incontinence pads day and night. She was physically extremely vulnerable and how she moved around and where she went was very much controlled by others. Similarly, because Lionel had so many falls, he was also confined to his chair and could not walk without support from others and felt that his quality of life could be poor.

Lionel: *If you're not careful it becomes an existence rather than a life and that is not very clever ...Yes I've got a limited life but I've got a life*
[Source: Biographical-Narrative]

When Pauline, who lived alone, developed a chest infection she was alone in the house tending to her own needs. Her carer was unable to visit as she was also ill and Pauline felt extremely vulnerable and worried about who would come to her help if she did fall:

Pauline: *Wake during the night with a very sore throat, my dread to not be well and not cope here. My little cat is spending most of the time on my bed, she is a great comfort but couldn't help if I was in real trouble. Being very careful when moving about – don't want to fall! Feel quite vulnerable.*
[Source: Diary]

Janet explained how the risk of falling and the fear of the consequences had a detrimental effect in her confidence as she became dependent on walking sticks and other walking aids:

Janet: *Yes, I don't suppose anyone understands how it affects you mentally, you become knocked backwards...from being somebody, I was very active and now having to creep around with sticks and stuff*
[Source: Biographical-Narrative]

This vulnerability and fear left Janet feeling as though she was less of a person. She sees herself in a negative light now that that she needs support with walking. She sees a changing sometimes invisible self when she cannot move around freely in a social setting:

Janet: *... growing old is very much a question of adaptation, from being one sort of person to another sort of person, which is hard ... At first you don't realise what's happening, this is new, this old lady who can't do this and can't do that, it's not the old me I used to be I find it particularly when I go to something like the day centre ...you see one friend over there and another friend over there and you chat, well I tried that but tottering about amongst a crowd of people with two sticks is just not possible so I had to plonk myself down on a chair and then hopefully people will either come past me or see me, and I just sit there and try to not look fed up*
[Source: Follow-up Interview]

Yet in spite of the fear of falling many of the participants demonstrated a determination to do the best they could. In the earlier review I discuss Baltes and Baltes' theory (1990) that older people use selection, optimisation and compensation techniques in order to maximise gains and minimise losses and continue to engage in those life tasks that are important to them. Findings of this study confirm this as many of the participants used various adaptive devices and practices like walkers, hand-grabbers, walking frames, walking sticks, stair-lifts and hoists and had their bathrooms redesigned to install wet rooms so they can remain as independent as possible. Maurice for example slept in his rising chair every night so that he could lift himself out of the chair to go to the toilet independently so as not to wake his wife.

Beyond using adaptive devices, some participants talked of innovative ways of making sure they can continue doing things they always used to. Pauline for example had always loved gardening, yet her knee replacements meant she had limited mobility. She arranged for the installation of raised beds and garden pots so that she could carry on potting her plants and devised a system whereby her carer did the heavy work. She also needed to walk to the local shop to get her groceries and she was often in a great deal of pain, yet she was determined to carry on remaining independent and took pain-killers to help. This determination and resourcefulness was echoed by Janet who could not get to the shops at all. She ensured she got her weekly groceries by drafting a list of items, texting it to her daughter in Wiltshire who then ordered it on-line for delivery direct to Janet's house. Few of those that appeared to be in a position of despair, seemed to adopt any selection, optimisation and compensation techniques. For example for Susan and Paul, the fight to overcome their difficulties was lost

to the pain of their disability and the isolation they felt. They had almost given up the fight to carry on doing the things they had previously enjoyed.

Feelings of vulnerability extended beyond the fear of falling. A fear of losing mental faculties was also expressed by Margaret and by Janet. They were concerned that they were doing and saying things that did not reflect the person they used to be. Their loss of faculties was affecting their sense of self:

Margaret: *So I'm very conscious of getting older because of forgetfulness... last week I had my shower and in the afternoon and I realised I hadn't put any antiperspirant on, I've been putting that on since my teens.... so things like that and the constant fighting for words or names that I should know well, are constant reminders of the diminishing of powers.*
[Source: Biographical-Narrative]

Janet expressed great concern that her powers of communication were failing and worried that she lost her thread when talking to people:

Janet: *Oh it is, often have to sort of think of the words if I'm going to explain something, that's one thing I find difficult when I go to <social group> we go on and say what we've been doing, or explaining something, and getting the logical sequence of words is difficult... you can be in the midst of an explanation and something goes and you can't remember what you were saying*
[Source: Follow-up Interview]

Yet both Janet and Margaret spoke about the invaluable support they received from their carers as they prompted their memories and helped with confusion. However, for some, physical and mental decline left them conscious of how other people saw them, adding further to their feelings of vulnerability. Janet expressed a huge amount of self pride and dignity and at the same time disappointment that she now presents to the world a figure of an old lady who has diminished faculties. She felt just as vibrant and energetic inside and disappointed that others saw her as old. She asserted that she feels no different inside, suggesting Featherstone and Hepworth's mask of ageing (1989) that I discuss in the literature review:

Janet: *I went to the theatre, you know the one down the road, and there's a big lobby and bar, and I arrived I had a seat booked and it was filled with people having drinks and standing, and I had to charge through with two sticks, and I just said 'excuse me, excuse me' ...Awful! Yes, I felt poor old lady I feel like saying I may look like a poor old lady, but I'm not! I remember my mother saying that to*

me, I look 80 on the outside but I don't feel it inside!
[Source: Follow-up Interview]

Lionel attended the day centre each week. In spite of being 86, he felt like he was in the presence of 'old people'. He resisted being categorised alongside the other day centre attendees as 'old'. He felt singing songs in a circle was demeaning:

Lionel: *it's full of old people and I want a challenge and I don't want to sit in a circle and sing songs*
[Source: Follow-up Interview]

This echoes findings from Hurd's' study (2000) where older people fought against the stereotype image of people of their chronological age and attempt to distance themselves from their age group. Lionel seemed to be railing against any societal view that old age is associated with, in this example, any mental decline. This alludes to the role theory I discuss earlier. Lionel placed greater importance on a role that supported the competent, able view of himself. He was rejecting a role that was aligned to the view of others. Similarly, Susan felt that her disability meant that others saw her as inadequate. She was so self-conscious of her dependence on physical supports that she felt other people would stare at her. Consequently she would not leave the house:

Susan: *I don't mind being stuck in now, I like it because I have to really push to go out now....Yes well people stare at me....people think 'Susan is no good because she's on walking sticks' and things like that*
[Source: Biographical-Narrative]

Whilst Susan felt a need to withdraw from social settings feeling self-conscious, Margaret also expressed envy of others who were older but still more capable and Janet felt a degree of resentment and injustice when she saw more younger more able people going about their business :

Janet: *I always took it for granted being healthy and fit... I get very mad I am very aware of my deficiencies....I feel angry..it's not fair, when I see all the youngsters striding about I think it's not fair, make the most of it while you can!*
[Source: Biographical-Narrative]

Both Janet and Margaret found it difficult to accept they could no longer do what they used to and they expressed almost separateness from others. Kaufmann (1994) suggests that old age is not a distinct period in life and that there is continuity in the ageless self that meditates the

demands of the changes that take place in later years. Yet some participants' accounts suggest that they do not feel a sense of agelessness. They feel old as their emotional and psychological energies and capabilities decline.

As I progressed through the narratives, diaries and interviews another powerful theme emerging was a fear for what the future may hold. Some older people spoke of their current situation and of hopelessness. Some older people voiced concerns about their increasing ill-health and loss of physical and mental faculties. They talked of the uncertainty they face and whether they will suffer a stroke, dementia or whether they will even be here tomorrow. Janet expressed the greatest fear about the unknown:

Janet: *.. you don't know what's going to happen, you don't know if you'll
live to 100 or die next week... God forbid I might have another
stroke ...develop something like dementia or whatever
and then you're a sitting target*
[Source: Biographical-Narrative]

Margaret talked about a sense of loss as she gets older and the sadness she felt that in the future she would be unable to do the things she had hoped she might. The uncertainty of what the future holds prompted Pauline to talk about her Will and Testament and how she wanted to make sure her daughter would be able to fund her funeral. She feared that she could die at any time.

Getting older was for many participants a challenging and often very difficult time. The fear of falling dominated many conversations with descriptions of how lives were altered to accommodate the risk. Yet at the same time participants spoke of innovative ways of managing the risk so that they could continue doing as many things as possible. However, a strong theme that emerged was of change. In spite of efforts to carry on doing things they always had, participants acknowledged that their daily lives were so very different to before and that their vulnerabilities were so much greater. Furthermore, they also recognised that the way that others saw them had also changed and they expressed feelings of sadness, loss and a struggle to accept their new identity with others.

5.1.3 The home space

Participants also spoke about how much their home space was challenged when they had carers attending to them at home. In the literature review I described how, when someone is

in receipt of care, the home “takes on the characteristics of the skeleton of a house, rather than the nurturing nature of a home” Healey-Ogden (2014, p.76). Dyck, et al. (2005) suggests that the caregiver’s entry into the home challenges personal identity through its invasion of the home space. This happens at a potentially vulnerable time, when for many their social and geographical worlds are shrinking and home takes on an even greater significance when it constitutes their entire world. Physical limitations meant that they rarely ventured outside. The home is the space in which home-care recipients spend most of their time. In its ideal form, home is considered a safe, protected place where individuals feel in control and are able to express a sense of self in an intimate and supportive environment (Milligan, 2009). Yet some of the participants reported feelings of being ‘invaded’ and of their homes feeling like ‘nursing homes’ and ‘open houses’ as various caregivers enter their homes.

Susan spent much of her time at home and her home space was very important to her. It was where she had lived with her husband for many years. She had various carers who visited four times a day, seven days a week, yet she saw some of them as intruders

Susan: *They’re invading my privacy... they’re spoiling it... I don’t mind some of them, some of them I don’t like, because they come in on my privacy and I don’t like that*
[Source: Biographical-Narrative]

For Susan, the home has the potential to be a “haven of physical and emotional well-being.”(Bender, Clune and Guruge, 2009, p.135) yet her insights are reflected by Gott et al.’s observation that “strangers coming into the home represented an ‘intrusion’ ”(p. 464). The privacy of the home space is lost to the public domain when carers enter this space, potentially affecting feelings of well-being (Healey-Ogden, 2014). Korosec-Serfaty (1985) suggests that self is protected within the boundaries of the home, but self is in jeopardy when there is unwanted intrusion. Susan’s demeanour changes when strangers attend to her personal needs and she indicates a sense of violation of her body and her self.

Janet suggested that having regular carers that she knew well would reduce the feelings of invasion. Lionel was also disgruntled about how often strangers entered his home space. In order to make sure he was receiving the level of care he needed, he had visits from occupational therapists, social workers, doctors, community nurses, and carers. He and his wife felt that the characteristics of the home in which they have lived for over fifty years had changed due to the care he received. His wife said it felt like an ‘in and out day centre’ on some occasions, whilst Lionel reported:

Lionel: *It’s an open house .My house no longer feels like my home because there are so many different people coming and going.... I forget what they even come to see me about.*
[Source: Follow-up Interview]

Similarly Paul became upset when strangers entered the room where he was cared for. He was an 86 year old man who spent all of his time in his bed due to a back injury and carers visited four times a day. He felt he had no autonomy with regard to his personal space, but for him this was not only because he had numerous carers who visited, but also because the timing of care was irregular and unpredictable. He did not know when they would be coming into his room to carry out very personal acts of care echoing Dyck et al.’s claim (2005) that when someone is being cared for at home the boundaries between the private self and the social self become clouded. His wife told how disturbing this was for Paul no matter how good the care was.

Maurice spoke of a need to maintain long established home rituals and to feel as though he still had a sense of control over their personal space. He felt as though his personal space was being invaded when a carer came into the home and started to dictate how things should be done:

Maurice: *...she was coming in and invading our space... she was telling me what I could do and I knew exactly what I was up to and sometimes I've had to say to people 'I also live here!'*
[Source: Follow-up Interview]

He and his wife had a very strict regime for the management of the house, something they felt was absolutely necessary for Maurice's well-being. However, when one carer came into the home showing little regard for the systems they had in place, both Maurice and his wife felt disgruntled and felt she showed little respect for their home.

Some also spoke of a need to preserve a sense of home when their homes were equipped with various supportive devices such as hoists, walking frames and rising chairs and support staff were constantly visiting. Maurice claimed that at times his home felt like a nursing home with all the equipment that was around. In the lounge area, where he spent most of his time, there was a hoisting chair, a nursing bed, a walking frame and the downstairs bathroom was adapted to meet his needs. In many of the homes that I visited there were several pieces of care equipment taking up space in the lounge or dining area and it was difficult to ignore the fact that there was someone being cared for in the home space. When care takes place in the home and the private merges with the public, the relational space within the home can be compromised as regular family practices have to adjust to care routines (Gott et al., 2004). Home is a space of established routines, activities and meanings yet these are disrupted by care practices. It is not just privacy that is challenged, but also the sense of self. It is interesting to note that for each of the participants who expressed feelings of invasion, this was only when they felt unhappy with the person entering their home, either because they did not know them well or because care standards fell short. When carers are visiting, the way in which carers respect the home is relevant. It is when carers are insensitive and disrespectful of the older person's needs in this regard, that tensions grow. For some older people the sense of home plays a vital role supporting their emotional well-being. It is a place where the older person is able to express their individual identity and feel a sense of one's place in the world (Twigg, 1999). Home is a place where one can maintain a level of stability and security (Dyck, et al., 2005, Healey-Ogden, 2014). Home is where the older person is able to maintain their personal world as they choose, and to exercise their independence and autonomy. Older people are not a homogenous group with identical emotional and physical needs. They each bring to the caring dynamic a unique history that influences how they experience care. Their personal traits may have endured since their much younger years through a life time of changes and challenges. For some these idiosyncratic needs and wants cannot be

compromised by their increasing years and by the fact that now others are contributing to their care in their daily lives. Others embrace flexibility and adaptability far easier and for some the challenges of life have equipped them with greater fortitude and endurance that helps them now they are older and more infirm. For others the challenges of being older and being in the cared-for role feel overwhelming and they struggle to remain positive.

Furthermore, for some their confinement to their home means that they feel they have lost a sense of autonomy and control over their reducing space in the world, a theme that emerged in the literature and became evident in the findings.

5.2 Autonomy in care

Maintaining control over personal environments and own lives was a theme that emerged across the interviews and in the diaries. Participants in general needed to feel they could still make decisions about their daily activities and how their homes were organised. Collopy (1995) draws the distinction between decisional autonomy and executional autonomy, that is the ability to make decisions about one's care and furthermore the ability to actually bring those decisions to fruition independently. Collopy (1988) goes on to suggest that older people see independence and autonomy not as a measure of their functional ability but rather the extent to which they have control over their world, the freedom to make one's own decisions and choices, and how seamlessly their care features in their personal worlds. Eleven of the seventeen participants in my study talk about how having regular carers allowed them to develop relationships of trust and comfort and how this helped them to have more control over their lives. Many also spoke of how the timing of care visits impacted on their feeling of independence and autonomy, with lateness and unpredictability of visits impacting on their daily routines. Participants also spoke of how care that is strictly task-centred and inflexible fails to adapt to any change in their needs or personal circumstances, thus depriving them further of autonomy and control. Management of their finances was also important for some older people and they talk about the way in which organisations manage the funding of care and that it leaves them feeling confused and feeling they have no control over how and where their money is spent. Altogether, these issues leave some feeling they have lost control and independence, which in turn increases their feelings of vulnerability and dignity.

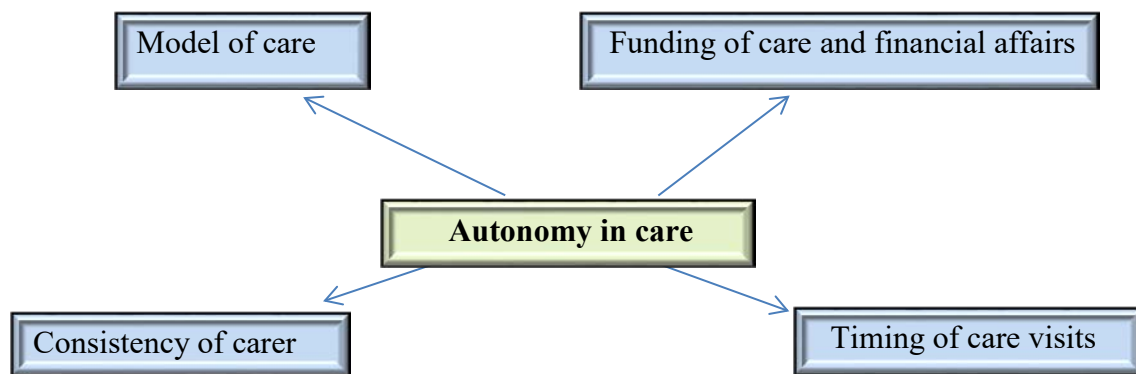


Figure 13: Autonomy in care and sub-themes

5.2.1 Consistency of carer

Participants spoke about their experiences with regard to the consistency of carers and the extent to which they were affected by the number of carers that attended and whether they were previously known to them. With some participants receiving up to four visits a day, seven days a week, it would be difficult for the same carer to visit each time. However, some saw a number of carers throughout the week and had little or no awareness of who was going to walk through the door to deliver what was sometimes very personal care. In some cases new carers were complete strangers. My findings have shown how having strangers entering the home space affects feelings of autonomy, and participants have voiced strong opinions about how important it was for them to have the same carer or group of carers attending their needs. They spoke of developing friendships, feelings of trust, familiarity, of comfort, and well-being, and of feeling valued and ‘lifted’ when they were attended to by carers they knew well. They spoke of how their feelings of dignity were affected by the relationship they had with the carer and how they felt about new carers who they had not met before attending to their very personal needs. They also spoke of the advantages of having the same carers who understood the routines of their care, who understood their needs, who did not need to be told each time where things are or how to carry out acts of care.

Some participants also talked about how care organisations manage the rotas, and allocate carers and keep them informed of who will be attending, and whether they introduce them to new carers they have never met. On the other hand, some participants spoke of how they were perturbed when new carers were allocated to their rotas and even more concerned when they did not even receive a rota and had no idea of who would walk through the door. Having

a stream of different carers was the greatest threat to their autonomy, especially when they were new carers of whom they had no prior knowledge. Susan was frequently visited by carers she had not seen before. On the other hand she was also attended to by carers with whom she has developed very strong relationships. The difference in her demeanour when she talked about either type was markedly different. Her face showed anger and she spoke with frustration when she recounted stories of how unknown carers tended to her personal needs. Yet when she spoke of her long term carers her face lit up:

Susan: *That's right, yes she does, and she leaves me on a high. They never go out of the door and leave me without a smile on my face*
[Source: Follow-up Interview]

Her husband agreed that her regular carers left her feeling mentally lifted and that this positivity would last for some time after they had left. Indeed, when Susan spoke about her regular carer her manner changed. She lifted her head, she laughed, and she had an air of joy about her that I had not seen. It was almost as if when Susan was attended to by this carer she had the chance to reconnect to the way she used to be, gregarious, outgoing, laughing and smiling. She was left feeling happier which in turn left her with greater feelings of well-being. Maurice also commented on how having consistent carers gave him a feeling of being at ease, of feeling comfortable with the other person and how having strangers carry out acts of personal care could be disconcerting :

Maurice: *I think it's very important for any caring situation that you must have this rapport between you and the carer because otherwise you're aware of each other; you feel this slightly stand off situation*
[Source: Follow-up Interview]

Lionel and Susan also spoke of feelings of dependability, safety and trust. Yet participants also spoke of how the regular carer was able to develop an insight into their needs adding to their feelings of trust and security. This insight and understanding that the regular carer was able to offer proved crucial when Susan, who suffered from emphysema, fell seriously ill and Grace her regular carer detected something was wrong. She insisted on calling the Doctor. Susan spent the next two weeks in hospital with pneumonia. It was Grace who intervened perhaps saving her from a worse fate. Susan's husband commented that because the carer knew Susan so well, she instantly knew that something was wrong and insisted the Doctor was called.

Dignity was also an issue when we spoke about consistency of carer. Susan talked about how, when they received personal care, a new carer would leave them feeling self-conscious and lacking dignity. She would often refuse to have a shower in front of someone she had not met before, which could have unfortunate consequences:

Susan: *Had a new carer today ... I feel rather self-conscious and asked for her only to give me a towel-wash.... I felt uncertain. She did not introduce herself on either occasion and because of my wariness of her I did not let her shower me.*
[Source: Diary]

In the follow-up interview, Susan's husband told of how his wife struggles with incontinence which adds to her loss of dignity. The lack of introduction by the new carer did not help the situation. Having someone she had not met before attending to very personal acts of care and at the same time not knowing the carers name proved disconcerting for Susan. Furthermore some carers did not even look at her or talk directly to her when attending to her needs, leaving her feeling insignificant and as though life was not worth living:

Susan: *Well people come in and look over my head ... They look over my head and talk to <husband>. They don't bother with me, I'm not there.... I always feel guilty, it's always my thought, and it's a privilege for me to be on earth, you know, they make me feel I shouldn't be here.... just not be on this earth*
[Source: Follow-up Interview]

Poor communication on the part of the new carer coupled with lack of familiarity not only affected Susan's feelings of worth and her sense of self, but also left her and her husband feeling they had little control over how her care was delivered.

However, consistency of carer did not always mean the relationship was positive and having a regular carer that did not care well also proved challenging. Margaret had a carer for many months but the relationship soured and Margaret suggested the carer bullied her, making her life very uncomfortable. Clare too had regular carers but the relationship did not enhance Clare's sense of control over her personal world. In fact, I witnessed during the data collection, how carers took control of her involvement in the study by removing the diary from within her reach. When Clare and I had finished the initial narrative enquiry, I asked her if she was happy to complete the diary. She was very keen and she asked me to leave it beside her so that over the next two weeks she would write down any interesting care events and make her comments and she signed the participant consent form accordingly. However,

when I returned to collect the diary she was disappointed that she had been unable to record anything as the carer had taken the diary away and refused to return it to her:

- SH:** *So I left the diary with you and I think you were quite happy about filling it in*
- Clare:** *Yes I was going to I can't get up to it...they looked at it, and they said everything goes in there <the carers' journal>, you're wasting your time...I explained what it was about but of course they wouldn't give it to me so I said can I have the diary please, they said well it's all in there <the carers' journal>, it's all in there, we haven't got time*
[Source: Follow-up Interview]

It was not possible for me to explore with the carers why they had taken the diary away, although there are pressures on carers in terms of time. Yet, in preventing her from doing something she was clearly happy to do, they deprived Clare of her autonomy and what is more, they did so in her own home.

In spite of Margaret's and Clare's experiences of consistency of care, the experience of most participants was that having regular carers facilitates the development of strong relationships. Furthermore, regular carers can also become familiar with the individual and personalised routines of care. Fjordside and Morville (2016) suggest that when there is continuity in the relationship, the carer develops greater competence and understanding of the routines of care and there is then greater opportunity for the older person to make autonomous decisions about their care. Regular carers have the opportunity to get to know where things are, how things should be done and how the older person likes their care to be delivered. Some participants spoke about how this familiarity not only gave them a sense of reliability and continuity, but also meant they felt they had some control over their care when they did not have to keep explaining the care plan to new carers. Fjordside and Morville (2016) go on to suggest that when an older person has to keep explaining their needs to new carers they find it such a struggle that they might put up with unsatisfactory care. Yet older people can be placed in the position of being constant training instructors for carers. Karen was concerned she sounded 'bossy' when she had to keep explaining the routines of care, whilst Davina struggled to remember what she should tell the carer and in which order. Clare also felt uncomfortable having to explain to new carers where things are, but she also felt embarrassed for them as they struggled to find things they needed:

- Clare:** *What about your underwear? I say well isn't that there on the*

chair? Oh yes. You spend your life shouting at them Yeah, poor girls
[Source: Biographical-Narrative]

However, when new carers were unfamiliar with the finer details of the care routine they could cause pain and discomfort. Maurice struggled when new carers rubbed his legs in the wrong direction causing him discomfort, whilst Susan also talked of how new carers might not know how she liked to be touched, and could cause her unnecessary pain:

Susan: *The new carer who came tonight is the one with long nails and even though I told her I was in pain she rubbed me very hard and I had to tell her to stop.*
[Source: Diary]

A further benefit of having carers who knew the routines of care was that they completed the tasks quicker which allowed them time to talk something that Susan valued :

Susan: *Everything at breakfast and lunch was spot on. Grace is only here the same time as everyone else but gets everything done, always perfect... and she always has time for a good chat.*
[Source: Diary]

Findings indicate that the relationship that develops with the regular carer promotes not only feeling of well-being, familiarity and trust, but also plays role in the supporting the older person to make autonomous decisions about their everyday lives. However, when the regular carers were unable to attend it was important to participants that they were told before the visit and that they had been previously introduced to a new carer. Many participants receive weekly rotas that list the times they would receive their visits, along with the name of the carer attending. In many cases the regular carers would be assigned and would therefore be known to the older people. However, in some instances not only did the organisations fail to issue rotas at the start of the week, but they also assigned new carers without any introduction. Susan found it particularly disconcerting when a new carer was not introduced to her by the care organisation prior to the visit, and when the stranger did arrive they did not introduce themselves either:

Susan: *I wish they would tell me who they are.... makes me annoyed and angry because I don't know who I'm talking to. It could be a man or woman off the street. It makes me feel like a baby again*
[Source: Follow-up Interview]

Eva complained that she did not always receive weekly rotas, and having strangers entering her home also made her feel anxious for her safety to the extent of fearing for her life. These fears could be allayed, to some degree, if she had received a list from the care agency of the carers that were due to visit:

Eva: *I feel I should know, I should know whose coming... I should have what I used to have which was a paper with 5 days written on it*
[Source: Biographical-Narrative]

Karen as well as Clare lived alone and they felt particularly vulnerable to the risk of intruders. Clare was immobile, being unable to get out of her chair unaided. She was left on her own between care visits for many hours.

Clare: *it's just that all the doors are always unlocked they've got to be for the girls to get in.... you put the light on and people go past and see you sitting here on your own and they think that old dear's been like that the last three nights and they could just walk in I do get quite nervous*
[Source: Follow-up Interview]

It was unclear why Clare's doors were left unlocked since most participants have a key safe system whereby keys are kept in a small safe on the outside wall, meaning that carers can let themselves in but doors remain locked between visits. When I visited the doors were unlocked and she called for me to enter when I knocked at the door. Yet this oversight meant that Clare was left feeling extremely vulnerable.

The importance of having consistent carers was a strong theme for many participants and there were clear examples of how this promoted feelings of autonomy within their lives. This consistency developed feelings of trust and familiarity and increased feelings of well-being and of feeling valued. A regular carer left participants feeling that they had some control over their lives when routines of care were maintained and they did not have complete strangers tending to their personal needs.

5.2.2 Timing of care visits

Typically when a care assessment is completed, the care recipient has the opportunity to specify the preferred time of the visits, considering such things as daily routines, personal needs and the role of informal carers. Sometimes older people are unable to take themselves

to the toilet and so need an incontinence pad through the night. It becomes crucial at what time they are helped to bed and when they are helped back up again in the morning. Often they receive the earlier calls so that they are not left in bed unclean for longer than is necessary. Equally some have health conditions, for example diabetes, which means they must eat at regular intervals. If they need help to prepare food, the timing of the care visits is crucial. These very personal issues all have an effect on the degree to which the older person feels they are able to manage and control their life.

However, it is not always the case that carers' visits fit in with such needs and some are left feeling stranded with no control over their very personal worlds. It is not simply the fact that calls may be late, but it is the not knowing that causes great concern. Having to lie in bed in a soiled pad unable to move proves difficult in itself, but this is exacerbated by the uncertainty of when the carer will call. There is no sense of personal autonomy.

The assessment will also determine how long each visit should be, based on need. I explored with some participants how they felt about the time that was allocated and the time actually spent with them. Whilst some were happy with the timing of visits some were concerned that not only was insufficient time allocated at the very start but that carers also cut short the visit to get to the next call.

When older people, are dependent on carers to help them to get out of bed, to wash, dress and eat, the times of visits consequently have an effect on how long older people are in bed, when they take the medication and whether they eat at regular times. Lionel and his wife spoke of feelings of abandonment and desperation when, on one occasion, a carer did not turn up until 10am even though he had been taken to bed at 9pm the previous evening and he wore incontinent pads at night. Susan relies heavily on her carers not only for toileting, but also for when she has her meals and takes her medication, routines that are mutually dependent. A carer being late can have a detrimental effect on when she receives her crucial medication. Listening to the voice of the participants, it became clear that the lateness of visits has the potential to disrupt daily routines and cause distress. However, it appears that for some participants it is the uncertainty of when the carer will visit that worries them. Not knowing if they will turn up on time leaves them waiting around concerned about what to do if they do not turn up at all. Lionel's wife told of how they were left feeling confused and abandoned when they did not know when or if carers would be visiting. These feelings of uncertainty were echoed by Lionel:

Lionel: *Carers do not call if they're going to be late*
[Source: Biographical-Narrative]

Susan also felt frustrated and angry when carers were late without any notice and Clare expressed some concern about the unpredictability of visits. Yet Margaret highlighted how autonomy can be threatened when carers fail to communicate when they will be attending:

Margaret: *No reply from <carer> about whether she can make it on Wednesday, may have no help tomorrow. 10pm still nothing from <carer>*
[Source: Diary]

When a carer is late this can also have a knock-on effect on what the older person plans to do for the rest of the day. For example, some participants need to be helped out of bed, washed, dressed, fed and in the wheelchair ready for when the bus arrives to take them to the day centre. Often the bus driver is not insured to help the older person into their wheelchair and consequently, if the carer is late then they simply cannot get to the day centre that day. For many the day centre is their life-line, their only connection to the outside world and depriving them of this opportunity can affect their feelings of isolation and loneliness. Clare, for example explained how she missed the day centre visit because the carer was late and she was not ready in time for the driver. Similarly, Violet who was blind and lived alone visited the day centre four times a week, yet two days a week the carers were not able to get to her in time for the bus. Her daughter-in-law explained how, on those days, Violet would get herself ready in spite of the associated risks. It became clear throughout the interviews that even if carers did arrive on time, the dependence on the carers' punctuality created some stress for participants who were expecting to be ready for the day's activities. Eva talked of how she felt she was 'lucky' if she was ready on time, whilst Karen worried that when her regular carer was taken ill and the care organisation had to find a new carer at short notice that she would miss her slot for the driver.

The timing of calls seems to be crucial for older people being cared for at home. Late calls leave them often stranded without basic care for many hours but also they can have a knock on effect on daily routines, depriving them of opportunities to meet with others. Yet the uncertainty of when carers will visit seemed to have the greatest impact on autonomy. Not knowing when they will be helped to dress, wash or eat caused a great deal of distress for many participants.

5.2.3 Model of care

A traditional task-centred model of care delivery means that care needs are assessed, standardised tasks are identified and time is allocated to meet those tasks. Often care is defined into neatly packaged precise time slots in which clearly defined tasks focus on purely physical activities of daily living. However, in 2005 the Green Paper 'Independence, Well-being and Choice' proposed that the preferred model of care was to be individualised, outcome-focused care that centres on the importance of consumer choice and control with clear measurable outcomes. However, the implementation of the outcome-focused model has not been universal, and the task-centred model is still widely employed.

I was interested to evidence the model of care that is used across participants, and how they feel about the type of care they receive and the extent to which it impacts on their choice and control. Some spoke of strict task-centred care that rigidly adhered to the care plan, whilst some spoke of carers going beyond the prescribed duties to provide additional help and support. Needing help with acts of daily living can by its very nature threaten autonomy, dignity and feelings of independence. Some older people reconcile themselves to the fact that they need care and that their autonomy may be compromised. When carers attended they typically worked to a fixed time. They completed the tasks that were listed in the care plan before moving on to their next call. For some participants this meant that tasks were often hurried and there was little time to sit and talk and provide the older person with an opportunity to communicate with another person. In the worst case, it means that jobs were rushed and not completed with due care and attention. Susan's husband reported that if some carers found themselves running late they would rush Susan's care to make up some time. This left him feeling as though his wife was not being cared for properly and when one particular carer seemed to take great pride in the fact that with Susan, she could finish early and make up some time, it further added to his frustration.

This free time was an ideal opportunity for the carer to focus on Susan's emotional needs and to engage with her, something that Susan so desperately needed. In this instance, the outcome for Susan was disappointment and further feelings of abandonment and isolation.

Similarly for Eva, when the carers completed the activities on the sheet in just five of their allocated thirty minutes, they missed the opportunity to spend time with Eva who also felt isolated and lonely. It seemed that carers were rushing the visit, removing her tablets from the

dosset box and leaving them with her to take once they have left. Since Eva displayed signs of the very early stages of dementia, there was the vulnerability that she would forget to take the medication. Elaine's daughter explained how Elaine was very lonely and wished that the carers could sit and talk to her rather than rushing through the tasks in the care plan. This would ease the feelings of isolation and loneliness rather than rushing off to the next visit and making up some time. Maurice and his wife sympathised that carers were under pressure to complete the tasks as quickly as possible to make up time. They suggested that care organisations did not allocate enough time for carers to complete the tasks and travel to their next visit.

Participants also spoke about the lack of flexibility when care is delivered using the task-centred model. Lionel's wife, was 86 and also in very poor health. She still managed the home including food shopping, cleaning, cooking and washing. When the carers came to tend to Lionel's needs, they usually went into the kitchen to prepare his meals, wash his dishes and clear away after themselves, tasks that were clearly described, amongst others, in his care plan. She felt aggrieved that, whilst they were in the kitchen, they were unable to help her by washing up any other, very few dishes that were in the sink, bearing in mind it was just her and her husband in the house. I left questioning this rigid adherence to a time-task care system and reflected on how this impacts on the confidence that Lionel and his wife have in the support he receives. They both felt constrained by care regulation and were perhaps left wondering what would happen if they needed help with anything more serious.

Whilst some participants spoke of how carers would do only what was on their list of tasks, and leave early once they had finished, others spoke of how carers would stay the full allocated time and do other things. Whilst Susan was disappointed with some of her carers, she sang the praises of one particular carer, Grace, who would stay the full time and sit and talk with her. It was clear this made Susan feel much happier:

Susan: *Again she chatted and stayed her full time. She has all the time in the world for us and never rushes to leave. If my whole caring was done by Grace I would be the luckiest person in the world but sadly I know this won't happen.*
[Source: Diary]

Janet also told how her carer did extra little things that made her feel safer and happier. For example bringing in some literature about how to protect herself from fraudsters, whilst Margaret appreciated the extra little touches her carer brought to her care. Lionel had little

opportunity to go out of the house. His wife could not push his wheel-chair as she was older and in poor health. He was pleased when a carer had some free time and took him out of the house. He was also impressed when a carer gave him extra support beyond the task list, including when he needed his toe nails cut. The carer spent time ringing the relevant agencies to help. Violet, who was blind, struggled to manage the home. Her daughter-in-law reported that carers give her extra support that was not prescribed in the care plan, leaving notes to let her know Violet was running out of any supplies, or if she needed extra care, for example with nail-cutting.

Working rigidly to a tight list of tasks seemed to leave participants feeling rushed and often other needs were not taken into account. This left some feelings vulnerable should anything need doing that was not previously prescribed in the care plan. When carers took the time to consider other needs, including supporting through talking, they left some participants feeling valued and more confident that if something should go awry, it would be managed.

5.2.4 Funding of care and financial affairs

Participants had a range of funding arrangements. Some were self-funding and they approached either the Local Authority or voluntary organisations for advice about care providers. Some were dependent on state funding for their care and it was the Local Authority commissioning team that chose the care provider. Others were in receipt of a personal budget and were able to decide how to spend their allocated funds and choose who would deliver care. However, there were some participants who were confused about the how their care was funded. They did not always know who was responsible for choosing the care provider, whether they paid for their own care or whether it was partially or wholly funded by the Local Authority.

I was interested in how these different funding styles affected the way in which care was delivered and ultimately how this impacted on the older person's feelings of having choice and control.

Margaret was the clearest about her funding arrangements. She needed approximately ten hours of care each week, and has a personal budget, receiving a sum of money as a direct payment that she can spend as she chooses. She chose her carers herself and decided not to use a care agency but to select her carers personally from recommendations, advertisements etc. She felt she had a high level of control over who comes into her home, and she recalled

how, when she was unhappy with a carer, she was able to terminate the arrangement and choose another one more suitable. This meant she was able to develop a strong relationship with her personally chosen carers and this was reflected in her positive account of the quality of care. She was also free to decide how to spread care across the week and often she would choose to use her allowance to go out with the assistance of her carer to the shops, to the cinema etc. This meant that she was less isolated and had support to continue doing the social things she used to.

Susan also had a personal budget and received direct payment. Her care needs were greater than Margaret's, with carers attending for approximately three hours each day Monday to Sunday. Her care was provided by her chosen established and national care organisation, but she did not always have any control over which carer would attend. This caused a great deal of frustration and disappointment. She had developed a strong relationship with Grace yet, because of the extent of care, Grace was not always available to attend and other carers would be allocated. She also needed a great deal of personal care and the allocated funds were only enough to meet those needs. Hence there was little flexibility in the type of care that was delivered. She had little opportunity to ask the carers to take her outside for example. In this case, having a personal budget did not seem to provide Susan with the flexibility of care that Margaret benefited from. However, she had been able to exercise some degree of choice and control. She terminated a contract with a care agency because they were not performing well and she found an alternative.

Clare paid for her care herself but, for reasons that were not revealed, it was the Local Authority who decided which care organisation would provide care. Clare had little insight into this process of selection, but gave the impression she had little choice or control in this respect. Again Clare's needs were high, with carers attending for approximately three hours each day delivering personal care and an additional overnight carer sleeping in. She was aware that she funded her care and was particularly disgruntled when carers did not stay with her for the allocated time that she had paid for:

Clare: *It does annoy me when I pay for an hour and they spend 10 minutes.... well they don't spend the hour I pay for*
[Source: Follow-up Interview]

It seemed that even though she paid for her care, Clare was still not able to exercise control over how it was delivered, something that caused her to feel frustrated and angry.

Furthermore, her care proved to be wanting in so many ways as other findings across this chapter have revealed. Janet also paid for her own care which amounted to approximately ten hours a week. Unlike Clare, she was not dependent on carers for personal care. She approached a voluntary organisation which provided her with details of carers that she could employ. Like Margaret she had greater control over who entered her home and she had a positive relationship with her carers. On the other hand Susan's husband's suggested that because Susan's care is funded by the Local Authority she was disadvantaged, whilst a neighbour who self-funded had more influence over the quality of her care. Susan's carers would sometimes rush through her care to make up time, whilst they would stay the allotted time for their neighbour who self-funded her care.

Some participants were confused about the way in which funds were managed. They spoke of numerous agencies being involved and the quantity and complexity of the forms to be completed. Some simply did not know if they paid for their care. Davina was unsure about whether she paid for her care at all, whilst Maud was confused about the funding of care believing that her carers were all volunteers and did not get paid for delivering her care.

Karen and Margaret spoke of funding eligibility. Karen expressed concern that she needed additional care beyond that which she was entitled to and that she struggled without support at the end of the day to undress. Financial confusion and loss of control extended beyond the care package as participants spoke of how they feel they have no control over their money, with other people managing their finances on their behalf. Vera spoke about how her family had stolen from her in the past and consequently her money was being managed by Social Services. Sadly, her money was also stolen whilst it was in the care of Social Services by one of their workers. Clare was also vulnerable when it came to her financial affairs. Her niece supported her each night by sleeping in the spare bedroom between 9pm and 7 am each night. This reassured Clare that she had support if needed and she paid her niece £80 per night for this service. However, when Clare worried what might happen when her money had all gone, the niece replied that if she was not paid she would no longer support Clare:

Clare: *I say to her I'm running out of money, oh she said and I said what's gonna happen and she said well we shan't come we won't come if we aren't paid are we?*
[Source: Biographical-Narrative]

This made Clare feel vulnerable, as though her niece was taking advantage of her situation, a concern echoed by her GP. It was clear that Clare did not feel she had control of her finances and that she was vulnerable to possible exploitation and financial abuse. Davina reported that her son managed her financial affairs. However, she expressed disappointment that when she wanted to buy something she had to ask him for money, exacerbated furthermore when he asked her for money as he had none left:

Davina: *Yeah like he asked me yesterday, do you have any money in your purse? And I said no, but he hadn't got any as he had to pay for my taxi up to the hospital ... The only thing I mind about it is if I want any money I have to ask for it*
[Source: Biographical-Narrative]

Clare was also concerned about the security of her possessions when her niece's husband removed Clare's mobility scooter from her front porch:

Clare: *Yes yes well <niece>'s husband took it away and he's got it over at hers, I keep asking him to bring it back but he don't seem keen to, I wondered if he'd sold it*
[Source: Biographical-Narrative]

It was not possible for me to explore the reason for this. Perhaps it was for Clare's safety, as she had fallen from the scooter damaging her hip. However, Clare's concern that he had sold it suggested she felt vulnerable, and unable to have control of her possessions.

It seemed that few participants had complete control of their financial affairs. Many did not fully understand how their care was funded and whether they made a contribution. It was also clear that when they did pay for their care, this did not necessarily afford them greater control over the way in which that care was delivered. There was also evidence that the management of personal funds, and in one case their personal possessions, was also out of their own control, with family members taking the lead. For some, this was a welcome support, but for others, they felt they had lost yet another aspect of their personal autonomy.

5.3 Voicing concerns about care

When something went wrong with their care, eight of the seventeen participants expressed a reluctance to speak out. They talked about feelings of embarrassment, guilt, having little confidence and fearing a confrontation with their carer. Some found it easier to complain

indirectly to the office, whilst some participants with partners at home or supportive family had their concerns voiced on their behalf.

The Equality and Human Rights Commission (2011) reported in their study that approximately 25% of their participants lacked the confidence to complain. The reasons included not wanting to upset care workers. Breiholtz Snellman and Fagerberg (2013) also found in their study that older people receiving home care often accepted inadequate levels of care out of gratitude and loyalty to their carers. The Equality and Human Rights Commission, report (2011) also suggests that older people were worried about repercussions if they did complain. Carers may be less friendly, they may lose their care, care may be disrupted, or they may even be placed in a residential setting. They were also reluctant to admit they could not do things for themselves and at the same time felt that other older people were probably worse off than themselves and they did not want to place undue pressure on carers. When they did contemplate complaining about poor care, around one in five of the older people in the Equality and Human Rights Commission study (2011) struggled to understand the complaints procedure. They were also unsure about which organisation was responsible for their care, and if they had ever complained they had negative outcomes. On the other hand some older people were just grateful for any care they received and saw poor practice as inevitable.

I evidence through my findings participants who fall into two categories. Firstly those who did not complain when things went wrong during care and those who did speak out.

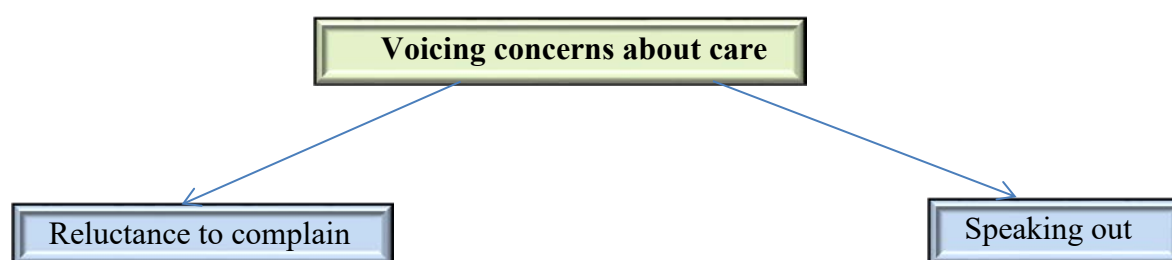


Figure 14: Voicing concerns about care and sub-themes

5.3.1 Reluctance to complain

Eight of the seventeen participants spoke about their reluctance to speak out when they felt unhappy about the care they received. Some spoke about their feelings of guilt,

embarrassment and having little confidence in their abilities to confront carers directly. In some cases they simply put up with poor care even when they were extremely unhappy. Others describe a fear of creating an uncomfortable atmosphere with the carer, or even that the quality of care may be jeopardised if they complained. Some used humour to bring to the carer's attention that something was not quite right, while others used tact and diplomacy skills. On the other hand, two participants recalled incidents of poor care and yet when I asked them whether they had complained, they retracted their earlier claims saying how good the carers were. I detected almost a nervousness that their concerns may get back to the carers.

Margaret talked about how she struggled to complain when her carer made a mistake. She not only put off mentioning it but she did so in such an apologetic way that she transferred some responsibility to herself:

Margaret: *I finally would get round to it, I think this went on for a few weeks... I finally managed to sum up the courage, probably tried to find some way to apologise for the fact my neck was so sensitive. So I think there would be an apology involved, something that meant it was beyond my control in a way... found it difficult to do without feeling I was criticising. Not easy because I don't want to offend her. My fear is that she will lose patience and feel annoyed/angry/criticised by me.*
[Source: Follow-up Interview]

She suggested that if she complained she would upset her carer, and so she tried tactfully to get the message across, avoiding placing too much responsibility on the carer for any mistake she had clearly made. Similarly, Maurice tried to brush off the carer's mistakes with humour even when his wife had to take over and finish the carer's job:

Maurice: *I suppose I was a little bit, I wouldn't say annoyed, but it was a case of getting him to do something to get on with it because he was just faffing about. I don't want to be sitting on a <toilet> seat any longer than I have to... Well I told him we're not going to do that again and that was alright... really was quite hilarious*
[Source: Biographical-Narrative]

Susan would not cope with any form of confrontation if she made a complaint to the carer. Her husband said that she would not have the confidence to complain, and if she did complain she would be left feeling guilty, blaming herself for what had gone wrong. She avoided mentioning anything to the carers when mistakes were made, which in turn created

tension and a breakdown in communication. Furthermore, Susan would end up feeling guilty if a confrontational situation did arise:

Susan: *I wouldn't argue, I'd just cry...so I don't talk to them and they don't talk to me*
[Source: Follow-up Interview]

When Karen had to bring the carer's attention to something they have missed in the care plan, she feels she was being 'bossy'. She struggled to take control and reverted to the care plan to manage the care delivery. The care plan listed the activities that needed to be performed but did not explain in detail how things should be done. Nevertheless, she suggested that rather than her raising a concern, the care plan should provide the carers with all the instructions they need. Clare mentioned during the narrative that she had been let down by the carers on several occasions, yet when I asked her whether she had mentioned this to them, she backtracked. She seemed fearful that by complaining, she may upset the carers, which in turn could affect the care she receives.

Clare: *Oh I don't need, I mean I'm quite well looked after I really am, I shouldn't want them to think I said otherwise...Oh no I mean I wouldn't like them to think I don't like her, 'cause I do, I like them all*
[Source: Biographical-Narrative]

Similarly, Vera was worried that she would come across to the carers as 'awkward' and that this would not help her situation. Some participants gave examples of very poor care, yet they tolerated it rather than complain. Susan made it clear at the beginning of the interview that she hated being called by the name 'Sue', yet when a carer repeatedly called her by this name, she said nothing and let it pass.

Some carers saw visiting Clare as an opportunity to take a nap in the chair next to her, rather than using their time to support her. Even though she paid for her care by the hour, Clare seemed unconcerned, taking pity on the carers for being so tired:

Clare: *they'd doze off to sleep...they put their feet up, put the chair back and they always say is there anything I can get you? ... the one that comes at night sometimes I have to wake her up and say come on I want to go to bed now <laughter> see these girls are so busy when they sit and relax its just too bad... I don't mind, it doesn't bother me*
[Source: Follow-up Interview]

Earlier in the narrative, Clare mentioned how disappointed she was that the carers had been late, did not get her ready in time and so she missed the day centre. Yet she retracted this claiming they are never late. Furthermore, when a carer turned up far too early, she could not put Clare in the wheelchair ready for the day centre. Consequently when the driver turned up she could not go with him, yet she relied heavily on those visits for social interaction, as it played a significant role in reducing her feelings of isolation and loneliness.

Four of the eight participants who expressed a reluctance to complain lived alone and had no family members to help them if there were any consequences. Generally, amongst those participants, there was a fear that if they did complain their care would be disrupted and the relationship with the carers might be in jeopardy. They felt vulnerable yet at the same time, any poor care was going unreported. Breiholtz Snellman and Fagerberg (2012) suggest that an older person might accept inadequate care out of gratitude and loyalty to others, diminishing their own needs and seeing others' needs as more important than their own

5.3.2 Speaking out

Whilst some participants were reluctant to complain when things went wrong, there were others who said they had expressed their concerns. However, rarely did participants voice concerns directly to the carers. They were either reported indirectly by telephone to the care organisation or to the carers by their partners, on their behalf. Interestingly, most of those who reported having made complaints about their care had partners living with them at home, or had extremely involved and supportive families. The Equality and Human Rights Commission (2011) also found that if older people did want to complain about care, they needed the support from family or friends.

Gillian gave the impression that she would complain if anything was wrong. However, she would not confront the carers directly but would rather pass it to the care organisation. :

Gillian: *Well if I wasn't satisfied I would tell them why...never had to make any complaints but if there was anything wrong I would 'phone the office, I wouldn't let it just pass*
[Source: Biographical-Narrative]

Some participants explained how it was their partners or family members who voiced concerns about their care. Lionel was unable to take himself to the toilet and so wore incontinence pads when the carers helped him to bed at 9pm. The carers then called in the

morning to help him to the toilet, washing him and helping him to dress. When Lionel was left in bed until 10 o'clock one morning, it was his wife who rang the office, complaining about the lack of communication:

Lionel: *Well they didn't turn up with no message at all*
[Source: Follow-up Interview]

Similarly, when Susan's carer was late, it was her husband that rang the office to complain threatening to cancel the care contract:

Susan: *He got on the phone, demanded to speak to the boss and promptly gave her a piece of his mind... and left her in no doubt he would cancel the contract if they put me second again. She apologised asked to speak with <regular carer> and told her to go back to the correct time tomorrow ...Just before she went she said she had learned a few valuable lessons today, one of which was to not get on the wrong side of my husband as he doesn't take prisoners!*
[Source: Diary]

Susan's husband believed that the reason she did not complain to the carers when they made mistakes, was because she lacked the confidence and so left any challenging to him. Susan's husband was vociferous when her care was inadequate. Sandman (2005) suggests that when an older person feels they have lost control of their situation, they decide to challenge as a way of regaining control. Her husband worked hard to retain control of Susan's care that he felt he was losing when the care agency were repeatedly late and he threatened to cancel the contract. Agich (2003) describes that the "countermoves" that care recipients may take, including cancelling services, are expressions of protecting self within the situation by taking control.

Maurice's wife also appeared to be quite direct with the carers, overseeing and managing the quality of his care. She suggested that this influenced how his carers performed, particularly the younger ones:

The care organisations have a responsibility to support those participants who are reluctant to complain when care falls short. The fact that the older person lives alone and has limited family support could perhaps be a good indicator that they might be nervous about raising any concerns about their care. They should perhaps be encouraged to speak out and given alternative ways of doing so, other than confronting carers directly or telephoning the care company. Review sheets or questionnaires could be made available which would highlight

any areas for concern. If there are others around to support any complaint, they should also be made aware of the complaints process, and speaking out about poor care should be encouraged. It seems that participants lacked the confidence and accepted care that was below standard, yet family members were more able and willing to speak out when something went wrong.

5.4 Social Contact

Chapter 3, the literature review, highlights that social isolation and loneliness can affect the physical and mental health of older people, contributing to poorer health and psychological well-being. Yet feeling part of a social network can promote autonomy, self-esteem and thus a feeling of well-being (Aronson and Neysmith, 2001). Aronson and Neysmith (2001) argue that underfunding and more stringent eligibility criteria can leave older people receiving care at home, feeling isolated and excluded from their communities. For many, the carer represents the only link they have with the outside world and the only person they see. They spend much time alone and when carers come into the home they enjoy the interaction and a true friendship can develop. For some participants their families, friends and neighbours provide a great deal of support, and interact with the carers, monitoring, managing and feeling reassured by the care that is given. Clubs and societies can provide welcome social interaction, with day centres playing a strong role for many participants. The interaction between care and social inclusion became evident across the interviews and diaries.

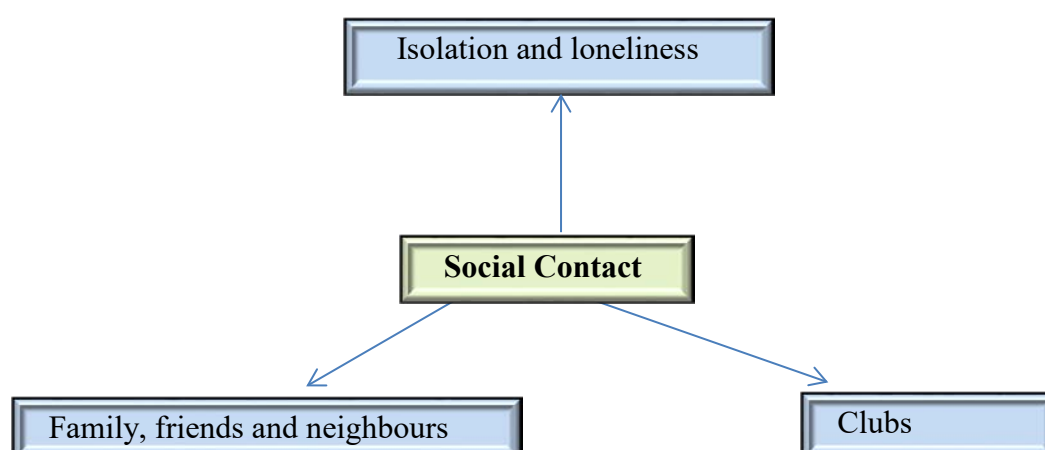


Figure 15: Social Contact and sub-themes

5.4.1. Isolation and loneliness

For some isolation was of real concern. Some cherished the visits from carers, particularly when they were feeling vulnerable, frightened and hopeless. Their visit punctuated long periods of being alone in the home with little communication with others and relieved the feelings of being cut off from the outside world.

When Pauline fell ill with a chest infection she was completely alone. Her daughter lives some miles away and transport proved difficult, meaning Pauline had no immediate support at a time when she most needed it. Her carer was also ill and could not attend. Pauline felt frightened and struggled to feed herself and keep hydrated. Feeling alone and vulnerable was also something that Clare discussed. She lived alone, could not stand or walk unaided and felt frightened when her lights failed and she was left alone in the dark. Davina struggled with the loneliness so much that she felt she had a poor quality of life. She tried her best to interact with the world by sitting at the window and waving at passers-by:

Davina: *I just say I hate my life*
SH: *What's the worst bit for you?*
Davina: *The loneliness*
SH: *You haven't got any nets up, so you can see the world go by*
Davina: *Yes, and they can see in I wave at people and they wave back*
[Source: Biographical-Narrative]

Janet too felt lonely and cut off from the world, particularly since she moved away from the centre of town into the suburbs where she believed there are fewer opportunities for interaction. She took every opportunity to attend clubs and societies to relieve the feelings of isolation. Clare talked about the long gaps between her visits to the day centre and the loneliness of sitting alone in her house for such long periods, and in spite of care visits she still struggled:

Clare: *Oh yes, I look forward to going, I think Friday when I come home*
I've got Saturday Sunday, Monday, on my own... Well there's
nothing wrong with the care, it's just sitting here alone for so long
[Source: Follow-up Interview]

Similarly, Margaret has calculated that as her carers only visit between Monday and Friday, she can spend approximately forty-eight hours with very little contact with others, whilst Janet explains that when she is alone for so long and does not talk to anyone, she feels her

powers of communication diminish and she struggles then to talk to others when she has the chance:

Janet: *Yes, well, I notice it myself with people who live on their own, with friends they tend to **talk** a great deal, and it's obvious because they don't get a chance, and I sit and talk to myself and yes, You've got to really concentrate rather than speaking freely*
[Source: Follow-up Interview]

5.4.2 Family, friends and neighbours

Across participants there was a variation in the degree to which relatives provided consistent support. Four participants, namely Susan, Paul, Maurice and Lionel lived with their partners who were their informal carers. Each partner monitored the way in which care was delivered and provided supportive care to their spouses. Lionel also has the benefit of a strong family to further support his needs. He takes enormous pride in the fact that his son helps him and his wife with the challenging paperwork associated with receiving care and managing his finances. He explains how important his family is to himself and his wife and that, in spite of his disabilities, they make him feel that he still has a good quality of life:

Lionel: *I think the biggest factor or influence in my life is having a strong family. Without that strong family I don't know what we got on. I think more than anything else it makes us feel we've got a life or sorts, it may not be an ideal life but we do have a life... If you're not careful it becomes an existence rather than a life and that is not very clever*
[Source: Follow-up Interview]

Vera and Karen, on the other hand, had no surviving family members, and the only care they received was from the visiting carers with no one else to check that all was well. Janet, Elaine, Gillian and Pauline did have families but they lived many miles away, making day to day engagement with the care service challenging. They gained some reassurance knowing their older relative was being well cared for when they were unable to be with them. Maud, Clare, Davina, Margaret, Sharon, Eva and Violet lived alone but had families living in close proximity, all of whom helped with their care and made sure they were being well looked after. For example, Violets' daughter-in-law explained how they intervene when care is not up to standard. Furthermore, various family members visited throughout the week including her granddaughter who helps with jobs around the house. After her husband died and before she needed care, Maud recognised that she was becoming isolated and so decided to move

nearer her son and daughter. Similarly, Sharon, who as an adult had lived with her parents, was left alone when they both died. She moved to be closer to her sister who not only arranged home care for Sharon, but also provided additional support, living just opposite:

For some participants, support extended beyond the family into the local community, with friends and neighbours extending a helping hand and a watchful eye. Sue had a friend nearby who visits, and Davina, who lived alone and struggled with feelings of isolation and loneliness, felt comforted by the fact that neighbours helped when she was in difficulty.

Similarly Janet, who also lived alone, called upon the services of her neighbour. Vera lived alone and talked a great deal about how many friends she had and how much they helped her with all sorts of tasks, including cleaning, washing and shopping. In the same way Karen speaks of the support she receives from a friend. Yet it was unclear whether she was a friend or a paid cleaner with whom she has developed a friendship:

Karen: *if it hadn't been for <name> who I've known for years, more a friend than anything else, she'll come in and, I mean for instance she'll mop my floors for me, does a lot of the dusting and the tidying*
[Source: Biographical-Narrative]

5.4.3 Clubs

Some participants spoke of the role that clubs and societies played in alleviating their feelings of isolation. Karen, who lived alone with no surviving relatives, discovered a group for older people who lived alone that met monthly. She took comfort from this opportunity to socialise. Maud lived alone and felt a need to meet with other people. She found an established and nationwide organisation that operated in the local area where she could go along to other people's homes to engage in conversation. However, through the narratives, interviews and diaries it became clear that the day centres were of huge significance with fourteen of the seventeen participants regularly attending their local day centre. For some they provided a 'lifeline', providing them with a vital source of social interaction and an opportunity to develop friendships, and they spoke extremely positively about the time they spend there. Vera believes that her regular visits enhanced her life, and she developed some strong friendships in the many years that she had been attending.

Vera: *I find that since I've been going to the day centre it changed my life altogether. That's all people, friends, you make friends with and everybody get on with each other and help one another, it's lovely*

[Source: Biographical-Narrative]

Maud seemed to appreciate the consistency that the centre provided, and that this facilitated the development of strong friendships. Even when Eva had a fall that resulted in her having stitches to her face, she was determined to go to the centre the following day needing the continuity and the companionship. She seemed to take great pride in her resolve which is clearly recognised by her day centre companions:

Eva: *All my face, I had stitches, they couldn't believe it when I said 'I'm still going to day centre' and <daughter> said 'yes keep doing that if you can' and I still went in on Wednesday and people were saying they all know me, people that live here, we all know each other and they said 'oh whatever have you done? I didn't want to shut myself away*
[Source: Biographical-Narrative]

Karen believed that the day centre provided her with the opportunity to engage with others, and break the silence of living alone that she experienced on the days she did not attend:

Karen: *Grab the opportunity, of saying whatever to whoever knowing that the rest of the afternoon and evening you'll be quiet.*
[Source: Biographical-Narrative]

When Pauline fell ill she was unable to go along to the day centre, somewhere she has been attending once a week for many years. She felt extremely disappointed and missed the company, the food and the activities the centre provided. Yet the opportunities that the centres provided went beyond the development of friendships and companionships. Some placed a high value on the additional support that the centre's staff provides. Karen, in particular felt reassured that the staff would help her if she struggled with an issue during the week. She relied on the fact that if something happened she could wait until she goes along to ask the staff for support.

Karen: *Oh yes, I mean <name> is wonderful, and I must say that the carers we've got up there are just lovely...there's nothing they wouldn't do for you ... I don't know what I'd do without them really, you tend to live for the days you go there.*
[Source: Biographical-Narrative]

Davina struggled to shower at home due to her physical limitations and she lacked confidence in the carers at home to physically support her. However, at the day centre she showered at

least once a week, feeling more confident in the staff's skills and abilities to help her into and out of the shower. This obviously had a positive effect on her personal hygiene.

Many participants who lived alone felt a need to interact with others, since they spent so many hours on their own at home feelings sometimes very vulnerable and isolated. For some attendance at the day centre provided respite for their partners who helped to care for them. However, Erikson's theory of gerotranscendence proposes that isolationism may in fact be preferable. The older person may begin to place less importance on superficial relationships and focus more on those close relationships. On the contrary many of the participants welcomed the opportunity to communicate with anyone, whether it be day centre staff, people walking past the house or friendly neighbours. However, Lionel did prefer not to go to the day centre and engage in what he considered meaningless activities. He preferred to stay at home in the comfort of his family. Yet he kept these feelings hidden as he knew his wife needed the break from caring for him. Nevertheless he grew increasingly disgruntled by the day centre visits and a stronger desire to stay at home. Recognition and understanding of his transcendent needs could have brought about an alternative approach. As Wadensten and Carlsson, (2003) opine, the well-being of older people is often measured by the extent to which they maintain their social roles and remain socially active. Hence, the carer who believes the older person's life to be passive and dejected may see a cure through activating the older person. However, Lionel's withdrawal from activity did not signify unhappiness and Wadensten and Carlsson, 2003 suggest ways in which carers could recognise behaviours and encourage and support older people in their development towards gerotranscendence.

Chapter 6

Discussion

The purpose of this study is to understand the older person's thoughts and feelings about care practices that are delivered in a way that respects their unique selves, as opposed to care that focuses purely on attending to their physical needs. Furthermore, the study seeks to understand the extent to which care that interacts with the self promotes feelings of autonomy and satisfaction with care. I recall now the research questions set out in the introductory chapter:

1. How are domiciliary care practices experienced by older people?
2. To what extent is domiciliary care delivered in a way that considers sense of self?
3. How do care practices link to autonomy and how important is this for sense of self?

Narrative methodology was used to gain insight into the complex relationship between care experiences, the meanings that older people apply to them and how they respond and to understand the social contexts surrounding care. Such insights are revealed in the findings Chapter 5, where it was evident that older people place importance on care that treats them as an individual and respects and values the meanings they have for different aspects of their lives. Furthermore it was clear that when care went beyond tending to purely meeting the physical body and home space needs, participants felt they had greater control over their environments and their decision making.

Through my findings it became clear that a care approach should be based on two tenets. Firstly a knowledge and insight into the importance of understanding and respecting the older person's continuing development of self, and secondly applying this knowledge to care through a positive, stable and consistent relationship between the older person and the carer.

Once I had completed my analysis of the data I revisited the conceptual framework presented in the literature review (see figure 1). I questioned whether the conceptual links still applied and whether I had revealed through the data any new concepts. In fact, as I progressed through the analysis, both Erikson's life stage theory and social constructionism gained resonance and helped in the interpretation of the findings.

Erikson's life stage theory proposes that the ego unfolds as the individual moves through the stages of life and that each new stage presents disequilibrium and challenges that the ego must master. Whether ego qualities flourish or flounder at each stage will determine how well the individual navigates later stages of life.

The social constructionist view is that the transient self changes and reconstructs itself to fit into the social context. More specifically, Stryker's interpretation of social constructionism is that self is socially constructed through the roles that are played out, with each role bringing forth a role identity. Identities are developed and maintained within the role relationships.

Hence the conceptual framework developed. Life stage theory helps in the understanding of the older person's continuing development of self, whilst social constructionism throws light on how identity is realised through relationships with others.

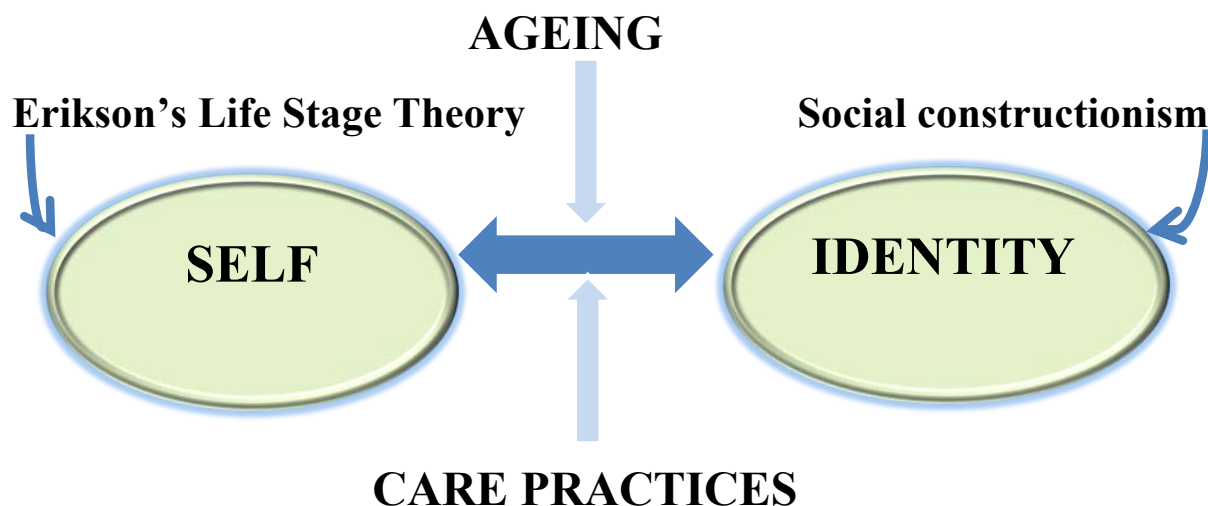


Figure 16: *Conceptual framework – further development*

This chapter will explore the evidence, presented in the Findings Chapter 5, that previous life experiences reinforced and strengthened personal characteristics and how for some it was these very characteristics that supported the experience of care. Care was enhanced when it was connected to the older person's self through understanding these characteristics and acknowledging them through care practices. Findings also evidence different views of getting older with some feeling frail and vulnerable, whilst others felt younger than their years. Care that considered these positions proved more supportive. Overall care that focused on the older person as an individual, promoted feelings of autonomy. There are also descriptions of how interactions with others and particularly with regular carers, impacted on the sense of self and

on autonomy. Often disability meant that they became more socially isolated with a more limited choice of the roles that could be enacted. As the cared-for role became the more salient role in their lives, care was better received when it was delivered by regular carers. Relational care promoted feelings of safety, security, comfort and rhythm.

Furthermore, it also became clear that when the carer understood the older person as an individual, so the relationship improved. Conversely as the relationship developed so the carer's understanding of the older person grew even more. In this way, knowing enhanced relationship and relationship also enhanced knowing.

This discussion chapter will now explore how the themes identified in findings address the research question, reflecting on the participants' individual experiences and by applying theory.

6.1 Understanding and supporting the older person's individuality

Getting older is a personal journey with each person taking to their later years an individual set of experiences that affect how they adapt to their later years. They have faced challenges through the stages of life, that have developed their very own set of characteristics, strengths and values (Erikson, 1963, 1968, 1982)

Gubrium (2001) suggests that the carer who takes time to understand and respect the older person's narrative, their life journey and experiences, will have a better understanding of the meaning that the older person places on aspects of their lives, and that this in turn will enhance the care relationship. Aronson (2004) describes how older people value 'being known' in that their personal biographies and their identities were known and respected. Byrne et al. (2012) also report how older people receiving care at home, place a high value on the carer focusing on them as an individual.

6.1.1 Ageism

Findings to this study indicate that an older person's earlier life experiences affect and influence their experience of care. Yet findings also show that care is sometimes delivered in a way that fails to respect the older person as an individual. Thompson (2007) suggests that when older people are treated as a homogenous group, with negative and often demeaning stereotyping, it marginalises and dehumanises them. Minichiello et al. (2003) propose that it is ageism that differentiates and sets older people apart from others in society. Some

participants to this study felt disappointed that their physical appearance and presentation meant that others treated them differently even though they often felt vibrant and energetic inside. This left them feeling separated from others. Minichiello, Browne and Kendig (2003) go on to suggest that ageist attitudes can be problematic for older people and result in a reassessment of self and a move towards seeing getting older as negative, rather than positive.

Whilst there was no direct mention of ageism across findings, there were several negative comments about being treated with little regard for individuality, and feeling like a number on a page. Similarly, Minichiello Browne and Kendig (2003) suggest that older people may not describe experiences of ageism either because they are unable to explain what is happening or they may not feel a need to voice such concerns. They also suggest that older people may not see themselves as old, and therefore may be reluctant to be identified with ageist stereotyping. On the other hand, they may feel, because of internalised concepts of older age, that being treated as old is perfectly acceptable and normal. Thompson (2007) suggests that as older people receive the socially constructed message that they are dependent, unimportant and a burden, they may begin to internalise those beliefs and acquiesce, accepting their lot.

The review of the literature in chapter 3 explores the different understandings of ageing, suggesting that there are tensions across the societal, cultural and personal levels (Thompson, 2006). Furthermore, the attitude of an individual carer or the older person might be informed by both psychological and sociological processes taking place at all three levels. The personal or psychological level is centred on beliefs, values and prejudices that influence not only how others treat older people, but also how older people may assimilate and internalise ageist messages and condone and even adopt, ageist attitudes towards themselves (Thompson, 2006). At the cultural level, consensus and conformation generate social norms and stereotypes and “taken-for-granted assumptions” or “unwritten rules” are processed (Thompson, 2006, p.27). Gendron et al. (2015) suggest that ageist language reinforces the stereotypical image of an older person as being frail and forgetful and that we develop generalisations and reinforce belief systems about the ageing process. With regard to the structural level, Thompson (2006) suggests that social policy creates and institutionalises discrimination. He goes on to submit that a cross level fertilisation of discriminatory ideology, in powerful dominant groups at the structural level, have the ability to influence negative cultural and individual beliefs about ageing through, for example, the media. The Joseph Rowntree Foundation (2005) report that social, political and economic factors create

and sustain divisions in society through the distribution of power and resources and “many policy or practice assumptions still see older people as a burden, a problem to be solved, a group denied the ordinary things in life because of the processes of ageing” (Older People's Steering Group, 2004, p.12). Focusing on domiciliary care, Twigg (2000) proposes that with the introduction of the Community Care Act in 1990 and the resulting commodification of care, the emphasis on activities of daily living meant that care became fragmented into packages of tasks, representing a “disembodied, etherealizing quality to the delivery of care” (p.5). Centering care based on purely the physical needs of older people, paying no attention to their psychosocial needs, further marginalises older people in receipt of care at home. Findings to this study evidence some care practices that take little account of the older person's individuality, suggesting that ageism permeates the cultural and personal levels, doing little to challenge the negative images of older people.

6.1.2 Gerotranscendence

Offering an alternative approach, Thompson (2007) suggests that an understanding of ageing through a spiritual lens will help to reframe ageing into a positive stage, where uniqueness prevails and where there is still potential for development. At first sight the term spirituality suggests a theological view, yet Thomson uses Canda and Furma's definition of spirituality as being “the search for meaning, purpose and morally fulfilling relation with self, other people, the encompassing universe, and ultimate reality, however a person understands it” (Canda and Furman, 1999, p.9). This implies that the development of self continues, and that older age is not a period of stagnation but rather an opportunity to reflect and reassess long held beliefs and thoughts. This resonates with Erikson's eighth ‘integrity versus despair’ stage of psycho-social development, where an older person might begin to try to accept their whole life with positive reflection. Integrity is achieved when one can fully accept oneself and take responsibility for one's life. The inability to do this results in a feeling of despair. Findings to this study indicate that in the face of changes associated with being in receipt of care at home, including potential for a redefinition of the home space, decline in physical functioning, and the loss of loved ones, there is a period of reflection and reassessment. The spiritual view also resonates with Joan Erikson's theory of gerotranscendence (1996) as the stage when older people transcend everyday limitations and concentrate on a more universal understanding of life. It is a time to revisit all of the previous eight developmental stages in an effort to achieve greater life satisfaction and to resolve any remaining unfinished developmental challenges to prepare ultimately for death. The older person takes time to

reflect on how she perceives herself and the world around her and “One becomes less self-centred and the sense of oneself expands to include a wider range of interrelated others” (Erikson, 1997, cited in Verbraak, 2000, p.13). Tornstam (1996), originator of the theory of gerotranscendence, claimed that it is a time when one's definition of reality based on a materialistic and rational vision is replaced by a more transcendental and existential view that leads to maturity and wisdom in old age. It is a time when integrity and purpose in life are shaped not by what one has achieved or accomplished, but by an understanding of one's self and how one is placed in the world. This transcendent vision of life involves a change in the perception of time, when the boundaries between past, present and future become blurred. The individual will avoid spending time on superfluous relationships, and a focus on materialism, but will rather seek to rediscover their inner self and move away from egoism to ego integrity.

The theory has been criticised for being essentialist (Jönson and Magnusson, 2001) in that it fails to recognise the diversity of the needs and interests of older people and runs the risk that people, who do not appear to transcend will have failed in some way. At the same time, however, it has been seen as a re-enchantment of ageing, providing a new and positive perspective on ageing. Rather than seeing old age, through an ageist lens, simply as a time of decay and decline, it is a view that sees it as a time when, in spite of frailty and dependence, one moves towards greater life satisfaction. Joan Erikson reflects on her own experience of gerotranscendence: “I am profoundly moved, for I am growing old and feel shabby, and suddenly great riches present themselves and enlighten every part of my body and reach out to beauty everywhere” (Erikson, 1997, p. 127).

Findings to this study resonate with Thomson's theory of spirituality and Joan Erikson's ninth stage of gerotranscendence. Many participants reflected on their lifetime achievements particularly around their family and their careers. They spoke with joy and enthusiasm about their children and their grandchildren, taking pride in the family they had grown and they enthused about the family roles they still managed to play, in spite of being physically curtailed by their ailments. They expressed positivity and of a job well done with regard to their careers and families, and they seemed to relish any opportunity to show photographs of family, to tell stories of their younger days and how they had managed even through difficult times to achieve so much. Some also spoke about the resilience and fortitude of earlier years that had helped them to survive and thrive. For some participants, however, they recounted their lives with sadness and confusion, as though they were still trying to understand and

accept things that had happened. They seemed to be in a stage of despair. Killick (2005) observes, however, that this spiritual anxiety can often remain unexpressed and unexplored. Minichiello, Browne and Kendig (2000) suggest that the reason why some older people may not disclose such feelings might be the forces of ageism that leave them feeling that they may not be worthy or have a right to speak about their fears and concerns. Yet, according to Erikson (1982), this process of reminiscence, meditation and self-examination is most effective when shared with significant others. Tornstam (1996, cited in Wadensten, 2005) suggests that the actions of care staff can encourage the process of transcendence. However, Wadensten and Carlsson (2003) propose that care staff should firstly reach an awareness and understanding of the process of gerotranscendence. They recommend that carers should try to recognise behaviours that might indicate that an older person is at this stage of their life. For example, some might be spending much time reflecting on their childhoods and events and episodes throughout their lives, take less of an interest in material things and prefer fewer and deeper relationships rather than many social contacts. They may have a decreased fear of death and focus on the past and present, rather than the future, recognising aspects of themselves they had not noticed before, and gradually withdraw from social activities. The writers go on to suggest that even when carers are able to recognise transcendence, there is a paucity of research into the practical measures that can be taken to support the older person. They suggest that it is the activity theory that informs most care staff and that life satisfaction of older people, is measured by the extent to which they maintain their social roles and remain socially active. This approach may impede the transcendence process and carers may even try to change the behaviours of older people.

Findings to this study evidence signs of gerotranscendence for some of the older participants. There was strong focus on childhood and on significant events of adulthood, and a very strong importance placed on relationships with family members. Some also evidenced a blurring of boundaries between past and present life, at times closely interweaving the two. It seemed that those who appeared to be transcending into a more existential way of being, were those whose physical functioning meant they spent less time away from home, perhaps giving them more time to reflect and consider their journey through life. However, I observed that those who were socially active and were able to independently visit friends, neighbours, and family, also spoke of such things, such as preparing for death, how events of childhood had contributed to their current selves and how they had navigated their way through some major issues in their recent lives, including that of transitioning into being cared for at home.

Wadensten and Carlsson (2007) report that some of these issues can be challenging for carers as some may not know how to respond to such issues. Yet with an awareness and understanding of gerotranscendence, carers can develop skills to support the transcendental process. These would include accepting that the signs of gerotranscendence are normal signs of ageing and allow the older person to talk about death if they choose. Research shows that some older people do want to speak about death and are not as concerned about it as when they were younger (Hallberg, 2004). Wadensten and Carlsson (2007) recommend that conversations should be centred on supporting the older person's development and growth through this stage. If the older person is needing withdrawal from social activities, preferring to remain at home, the carer should encourage and facilitate quiet and peaceful places and times and alternative activities. There should be an acceptance by carers that older people may not want to socially engage and thus should not be coerced into visiting people or attending social activities. Some participants to this study were not happy visiting the day centre, preferring instead to stay at home, but acquiesced as it gave their family members a period of respite.

Sundler et al. (2016) carried out a study with domiciliary carers exploring communication challenges that exist with older people in this setting. They observed that existential more spiritual matters were sometimes raised during the care sessions, and care staff found this challenging and often difficult to manage. The authors suggest that this may be due to a generational difference between carer and the older person, but they also suggest that the task oriented care model allowed little time to discuss issues such as ageing and death. Often, there was simply not time for carers to explore such matters, and when they were raised by the older person out of the blue, they had little time to prepare a sensitive and supportive response. Task-based care, places greater emphasis on completion of the prescribed activities than on communication (McCabe, 2004). Sundler et al. (2016) suggest that the training of care staff should include how to communicate with older people about existential matters. They conclude that this requires a cultural shift not only at the point of individual interaction but also at the organisational level and that care packages should include an allowance of time for carers to have these kinds of conversations.

6.1.3 The biographical approach

The narrative approach of this study was well-received by many of the participants. They appeared to personally gain from recounting stories about their lives including their much earlier experiences and how they had made the transition into being cared for at home. Many seemed to reflect on how they had endured difficult life experiences and how these challenges had equipped them with attributes such as endurance, positivity and determination that now help to support them as they receive care at home. They also spoke of the values that they hold dear and how these affected their experience of care. They had lived their lives with honesty, openness and reliability and expect their carers to be the same.

The use of a biographical approach in working with older people has received much attention in that it can be supportive to the care dynamic by helping the older person to feel at ease in the period of gerotranscendence. Randall (2012) writes that whilst ageism focuses on the biological ageing of the individual, the narrative approach sees ageing more positively as a biographical process where one grows old through a complex web of stories and that the stories continue, along with personal growth, until the end. He says that through the narrative we can “read our lives” (p.172), making sense of the lives we have lived, the world we live in, and ultimately to know ourselves. We are constantly reading and writing our own life-story in an on-going process of self-reflection and finding a meaningful way to connect the events and experiences and interpret them, in order to experience life as coherent, logical and meaningful (Coleman, Ivani-Chalian, & Robinson, 1998, Kaufman, 1994) which in turn helps older people to maintain their self-image and meaning in life (Borglin, Edberg & Hallberg, 2005). Furthermore, the story is socially constructed in that the different environments within which we have lived and grown have shaped who we are. Our story is co-authored by those with whom we have shared the journey, whilst we do retain a degree of agency and self-determination about how the story unfolds. Randall (2012) suggests that adapting to old age requires “not so much a good strong body, though this can help, but a good strong story” (2012, p.174). Through the narrative grows a wisdom where one can reconcile, reparatively, with difficulties in the past and learn not only *about* one’s own story but also learn *from* the story, reflecting on it from the perspective of self not only as narrator, but as self in all the various roles one has played. As Heidegger (1962, cited in McCormack and McCance, 2011) proposes we must first know ourselves, before we can understand our experiences, and

through questioning our existence we can begin to understand the meaning of our being, our self, our identity.

Clarke et al. (2003) explored how the biographical approach would support care and propose that in order to deliver care with the older person as the central focus, and care that goes beyond meeting purely the physical needs, it is necessary to understand the person as a whole. This must include understanding their wants, needs, aspirations, attitudes, values and their significant relationships. It is through this understanding that carers can gain invaluable knowledge that will affect decisions about the care they need. Narrative practice can play a crucial role in care (Taylor 2003, Clarke, 2000, McCormack, 2001). It is important to develop a clear picture of what the older person values about their life and how they make sense of what is happening. Findings to this study highlight how for many of the participants their very personal thoughts, feelings, values and beliefs affected how they felt about the care they received. Placing the older person at the centre of care, means understanding and appreciating the embodied self, beliefs and values. Others can know who I am through the personal biography (McCance et al. 2011). Clarke, Browne and Kendig (2003) also stress the importance of the biographical approach in developing a more holistic and positive relationship, between carer and cared-for, and how it helps carers to counteract ageism by encouraging respect for the older person's unique identity. They warn, however, that not all older people may welcome the chance to share their stories, and that they may feel uncomfortable without a relationship of trust and that storytelling may have negative consequences for some.

To summarise, the conceptual framework presented in the literature review explores the concept of self and identity. Looking through the lens of Erikson's life stage theory has supported the interpretation of findings and this discussion presents the advantages of an approach to care that recognises the stages of ageing and values the biographical approach. Such an approach understands the older person's thoughts and feelings about getting older and how this affects their experience of care. Furthermore it understands the meanings that older people hold for different aspects of their earlier, current and future lives and considers these meanings when delivering care.

However, the framework also presents a social constructionist view, focusing on the value of relationships within care and the roles that are enacted, as what makes our selves belongs "not to self-reflection but to the mutual recognition between two people" (Oppenheimer,

2006, p.199). The discussion will now present the interpretations that have been gained from looking through this lens

6.2 The importance of relationship and the regular carer

Suffusing findings has been the key concept of relationship. It pervades much of the data gathered, sometimes hidden between the words, yet at times the importance of the bond between themselves and their carers has been made abundantly clear by participants. Some spoke of carers being like family members, like true friends and they expressed feelings of despair at the prospect of losing them as their carers and this is particularly true, when so many participants were isolated.

6.2.1 Isolation

Isolation was a dominant theme across findings. Participants experienced feelings of isolation and loneliness, making the role of the carer particularly important. 65% of participants lived alone and the carer provided their main source of social interaction. This figure reflects the national picture in that 51% of all people aged 75 and over live alone (ONS, 2010), and 40% of older people say the television is their main source of company (Age Uk, 2014). Research explains that opportunities for social engagement decrease as functional ability declines and so the dependence on others for support with transport etc. increases (Timonen, Kamiya, and Maty 2011). Whilst for many older people, maintaining social relationships has been shown to enhance feelings of well-being as people grow older and particularly as their physical functioning declines, so their opportunities for social engagement also wane (Avlund et al., 2002). For many of the participants to this study mobility was affected by their disability. They reported difficulties in attending day centres, and visiting friends and family. For many this was problematic. Withdrawal from social activities is not always voluntary but due to functional limitations (Mollenkopf et al., 1997). Research indicates that for many older people such social isolation and loneliness has negative effects on both physical and mental health, (Tomaka, Thompson and Palacios, 2006). However, as the previous section of this discussion reports, withdrawal from social activities may be welcomed at a time of gerotranscendence and the need for personal reflection and solitude increases. This may also be due to failing energies and some participants to this study reported not wanting to socially engage because their energies were seriously depleted.

Within this context of social isolation, the carer has the potential to become a source of interaction and relationship. The carer may be the only person the older person sees from one day to the next (Equality and Human Rights Commission, 2011) and studies indicate that one-to-one support, either by way of a carer or befriender, can assuage loneliness, and that older people respond favourably both mentally and physically to this contact (Catten, 2002, Mulligan and Bennett, 1977-78). Furthermore, the intimate nature of care means that for many older people, having a good relationship with their carer is of high importance (Equality and Human Rights Commission, 2011). Findings to this study evidence the high value placed on the relationship with the carer. Some speak of them being like friends or even like family, and a lifeline for both those whose opportunities for social engagement were curtailed by their limited mobility and for those who preferred and chose to stay at home.

6.2.2 Relational care

In recent years, commissioners of social care have expected care to be person-centred (Care Quality Commission, 2017). The emphasis has been steadily moving away from seeing service users as passive recipients of care (Rose, 2003) and towards supporting people who use social care services to plan their own futures and to take a lead in planning all aspects of how the service they receive is delivered (Mansell and Beadle-Brown, 2004). The concept of person-centred care has, over recent years, become synonymous with best practice care (Slater 2006). Edvarsson, Fetherstonhaugh and Nay (2010) suggest that “current understandings of the concept largely rest on abstractions, conceptual synergies and personal opinion” (p.2612) and McCance et al. (2011) go on to claim that the term person-centred is used in a tokenistic way within health and social care and is used by staff who have little idea of what it means in practice..

Nolan et al. (2004) argue that a person-centered approach that places emphasis on personal autonomy is untenable when applied to the care of older people and “care standards for older people, that have at their heart a definition of person-centred care that focuses on meeting individual need, may well be misguided” (p.46). Individualism and independence are difficult to achieve when an older person being cared for at home has limited mobility and opportunities for social engagement. Nolan et al. (2004) suggest that person-centered care should recognise the complexity that underpins caring relationships and that there is a need to understand the interdependencies and reciprocities that abode within such relationships. As an alternative, they recommend a relationship-centred discourse, where the focus is on the

interactions between the caregiver and the cared-for and where there is an understanding of how relationships can influence the care experiences. Relationship based care is therefore concerned more with the interdependency between the older person and the carer. Focusing specifically on gerontological care, Nolan et al. (2002) identified six dimensions that underpin relationship-centred care in the Six Senses Framework. They argue that older people need to feel a sense of security, continuity, belonging, purpose, fulfilment and significance. Relational care that considers each of these issues will help to identify the structures and interactions that create and maintain positive relationships

6.2.3 The importance of the regular carer

On average, someone who receives care at home sees their carers for approximately 12.2 hours per week (NHS Digital, 2009). The participants to this study received care ranging from between 3 hours a week to 16 hours per day. When care reaches high levels it is important to consider the potential for the development of relationships between the cared-for and the carer. However, relationship building often depends on there being regular carers visiting the home. Findings evidence that when a new face appears at the door, the older person is faced with someone who is unfamiliar with the routine of care and their individual physical and psychosocial needs. They are virtual strangers and it takes time to develop a rapport, and a comfortable communication between the two. Having continuity of carer has been an important issue across findings, with thirteen of the seventeen participants expressing strong feelings about issues such as familiarity and friendship. Woodward et al. (2004) found that this was particularly true for older frail recipients whose mental and physical energies are low and who need help with highly personal acts of daily living, for example washing, dressing and toileting. Dignity has been a clear message for some participants to this study. Some spoke of the importance of the same carer taking them to the bathroom and how they felt vulnerable, embarrassed and uncomfortable when a succession of new carers helped them to undress and shower.

Findings to this study show that having a regular carer coming into the home also has an impact on feelings of safety and security. For some, being unable to stand or walk unaided, having people enter the home made them feel vulnerable and, in some cases, frightened particularly when they had no idea which carer would be attending or whether they might be a complete stranger. When participants had regular carers, they expressed feelings of safety and comfort knowing that it would be their regular carer and not a stranger at the door. Nolan

et al. (2004) take the 6 senses framework further and suggest that continuity of care will promote feelings of security. Those participants who have regular carers spoke of feelings of trust that came from the relationship that had grown between the two, along with feelings of comfort, familiarity and rapport. All of the participants who expressed any feelings about continuity of carer placed a high value on the warm feelings they felt for their carers. Some spoke of them being like family, like true friends. This echoes Nolan et al.'s claim (2004) that continuity of carer engenders a sense of belonging. Some participants gained a true sense of attachment, value, significance and worth from the relationship

There are practical issues too that arise when a new carer arrives. The new carer must read the care plan extremely carefully to understand the routine of care and even closer to find very individualized care preferences and practices. This is a real issue when allocated visit time is at a premium and it places great onus on the older person to explain the routine to new carers. Six of the seventeen participants spoke of how they found it frustrating and tiring to have to tell each new carer how they prefer care to be carried out. Furthermore, it took new carers longer to perform the tasks, impacting on levels of comfort and dignity, findings echoed by Woodward et al. (2004). It takes time for the relationship to flourish and for some participants, only then do they feel at ease and a sense of rhythm develops between the carer and the older person. The carer over time begins to understand the specific and unique needs of the older person and the idiosyncratic preferences that make acts of care more comfortable and easier to perform and receive. Many participants spoke of feelings of familiarity, awareness and understanding that came from having the same carers attending over a period of time.

Unlike Woodward et al. (2004) and Edebalk, Samuelsson and Ingvad, (1995), Francis and Netten (2004) found that continuity of staff and the development of a friendship was not always an issue of great importance to older people receiving home care. Some participants to their study reported being happy to have a range of carers, although they did express a preference for having seen them at some time so that they were not complete strangers. They placed more value on reliability, flexibility and staff attitudes, whilst thirteen of the seventeen participants to my study expressed a strong need for regular carers. One participant said that "a friendship develops as long as they've been doing the job properly" indicating that the quality of care is determined more by how it is delivered, than by whom, whilst another stressed the importance of reliability rather than continuity. Nevertheless the majority of

participants preferred to have the same carers attending and one participant was prepared to sacrifice communication, reliability, flexibility, staff attitude, in fact virtually anything, as long as she had the same carer. During the initial assessment and in on-going reviews, the care organisation and carer workers could establish individual need in this regard. They could find out whether the person values having a regular carer or whether this is not a priority.

Having a regular carer clearly appears as a high priority for many older people receiving care at home. It is inevitable however, that the carer will not always be able to attend due to holiday, sickness etc. Francis and Netten (2004) report that the biggest barrier to continuity of care is the care workers' unauthorized or unpredictable absences and sickness. Furthermore, difficulties in recruiting and retaining staff meant that there was a limited pool of carers to cover such absences. The study by these authors heard that care managers made best efforts to provide continuity by carefully planning rotas and that they warned older people that their regular carer would not be coming to visit, and ensured they introduced new carers before they visited. Yet findings to this study evidence that this is not always the case. That care organisations communicate well with the older person. Typically at the start of each week, each older person will receive a rota detailing which carer will attend and at what time. Some participants to this study reported these either not arriving or being in error and when a new carer arrived unannounced, they reported feelings of vulnerability, loss of autonomy and fear, particularly when they had not been introduced at any time and the new carer was a stranger. Francis and Netten (2004) suggest that communication with the care organisation is more a measure of quality of service than continuity, yet findings to this study indicate that communication and continuity are inextricably linked. Preparing the way for a new carer through introduction and information, could help to mitigate the anxieties felt by the older person at losing their regular carer.

6.2.4 Roles and supporting sense of self

Relationship is important to the older person receiving care at home, particularly when the opportunity for social interaction is so limited. Yet current literature has paid limited attention to the value older people place on this aspect of care. Findings to this study evidence that for many older people receiving care at home, the role the carer can play in the day to day lives of this group can be vital to their well-being and that this relationship often develops when regular carers are attending. Research suggests that relational care is not just about supporting

physical need but also emotional need and that when care becomes an integral part of the older person's life, the relationship becomes a source not just of care, but also of comfort and supports personal growth and development (Doyle, 2012, Crist, 2005). The analysis of this study indicates that there was a need for self to transcend the care experience, for the older person to feel they are not being defined by their need for care. Crist (2005) suggests that when a carer understands and accepts the older person as a unique being with personal beliefs preferences, wants, needs, likes and dislikes, only then can the older person's self be supported. She goes on to suggest that being defined as a care receiver was not consonant with the older person's image of themselves and that there is a need for expression of self through relationship. Furthermore, Doyle (2012) suggests that it is through relationships that one can experience one's uniqueness and authentic self and at a time when, for an older person, incapacity can challenge this authenticity, the care relationship can bring about an identity dilemma. Stryker (1968) proposes that identity is socially constructed through the roles that are played out, with each role bringing forth a role identity yet he suggests that an individual places greater importance, or salience, on some roles over others and that the norms associated with that role provide the person with a sense of meaning. Yet for an older person being cared for at home the choice of roles often becomes limited as they become more socially isolated. Their cared-for role within the caring dynamic often holds greater significance even though it may not necessarily be the one they wish to enact. The highly salient identity is not necessarily one that the individual wishes or desires to perform. "The salience hierarchy represents the situational self rather than the ideal self" (Burke and Stets, 2009, p.41). Krause and Shaw (2000) suggest that when an older person develops a deeper sense of meaning from the roles they enact, then there are more positive outcomes in terms of well-being with improved management of stress, better personal care management and stronger feelings of optimism.

Looking through the social constructionist lens of role theory, the importance of the nature of the relationship between cared-for and carer is clear. Not all older people will place such importance on relationship, and other issues such as flexibility and reliability will be of greater significance. Equally not all regular carers will be the source of positive relationships. It is impossible to legislate that all caring relationships will be positive at all times. However, findings of this research strongly suggest that encouraging relationships through providing regular carers enhances feelings of comfort and security and autonomy. The older person's need for continuity could be established at the assessment stage and in on-going reviews and

management practices, for example when the carer's rotas are drawn up. This should ensure such needs are met and regular carers are assigned to those who express such a need.

6.3 Understanding independence, dependence and autonomy in care

Participants to this study referred to the degree to which they felt in control of their lives, their environments, and their home space. As discussed in the previous section, for many having a relationship with their regular carers promoted feelings of safety security, comfort and autonomy. Yet for others, they felt they had little control about when, where and how care would be delivered, particularly when they felt little connection to the strangers that entered their home. I explore now the concepts of autonomy, independence and dependence and how they are experienced within the care setting

Being in receipt of care at home necessarily means that the older person can no longer carry out some activity and that they need help in doing so. Each of the participants to this study are unable to walk any distance and are lacking in physical strength, resulting in their need for help with doing such things as shopping, cleaning, washing and cooking. Furthermore, 47% of the sample suffer more extreme disability and are unable to get to the toilet unaided nor can they wash or dress themselves without support from a carer. This inevitably means that their independence is compromised and functional limitations and disability are major threats to independent living. Literature indicates that as their frailty increases and their functional ability declines, older people have even less influence on their everyday lives (Breiholtz, Snellman and Fagerberg, 2013, Glasdam et al., 2013, Boyle, 2005). However, the understanding of what is meant by independence becomes unclear as we see how it is so closely entwined with autonomy, dependence and dignity. It is essential that in order to deliver the best care one must understand from the older person's perspective of how it feels to be reliant on others and what aspects of care promote or inhibit feelings of independence, autonomy and dignity and how autonomy affects dignity. Yet our understandings of what these actually mean to an older person receiving care at home is limited (Haak et al, 2007).

6.3.1 Independence

The notion of independence within health and social care is one that has a challenging history particularly since the latter part of the last century, and professionals have sought to understand how it is perceived by carers and the cared for. The generally accepted understanding of independence within Western cultures is that it represents self-sufficiency,

particularly when it comes to money, emotions and physical strength. In the past it has had a strong masculine association with productivity, privileging self-reliance, self-regulation, control, and the ability to make choices about important aspects of one's life (Kaufman, 1994); Mack et al.'s study (1997) reported male participants associating independence with positivity, growth, purpose and mastery, whilst Sherwin and Winsby (2011) emphasise the rational free and self-governing individual. Within the health care setting the term independence is often referred to as "the level of a client's functional ability" (Crist, 2005, p.488). This socially constructed and almost atomistic interpretation of what it is to be independent was incongruent when looking at the experiences of participants to this study. So many were unable to walk unaided or take themselves to the toilet and self-sufficiency and independence were impossible to achieve.

6.3.2 Dependence

Dependence, on the other hand, is generally associated with incapacity, incompetence, neediness and helplessness (Baltes and Silverberg, 1994) and loss of independence contributes to feelings of worthlessness and low self-esteem (Kaufman, 1994). Benner and Wrubel (1989), on discussing dependence, suggest that "to be helped or be in need of help, means that one is incompetent, wrong, hapless, helpless or stupid" (p.187). The term dependence is rarely used in a positive way and is a concept that is generally seen as "cold and its connotations are almost entirely negative" (Fine and Glendinning, 2005, p.605) and represents an element of shame and of being shameful. Yet even though independence was impossible to achieve, participants to this study fought against dependence, demanding that things were done the way they chose and that the care organisation respected their need for routine and reliability. Sandman (2005) points out that as our executional autonomy diminishes, we may feel a need to challenge the care system, in spite of any repercussions to care, in order to regain some element of control over our lives. Participants to this study resided somewhere between the longing for independence and the necessary dependence on carers. Kaufman (1994) describes being frail as being in a battle between increasing dependence and decreasing independence. Sandman (2005) suggests that people may give up their struggle for self-determination out of a fear of being abandoned or of being a burden.

6.3.3 Autonomy – decisional vs. executional

Yet for some being autonomous did not mean being independent. The terms are frequently used synonymously, yet within the realm of social care the differences become more salient.

Whilst independence is closely linked to an individual's functional ability, autonomy is concerned with the person's sense of choice and control (Crist, 2005). Whilst participants' functional abilities meant they were no longer independent, as many needed help and support with acts of daily living, they were able to make autonomous decisions about how that care was delivered. In this sense, autonomy seems to mediate between dependence and independence. This becomes clearer when we consider Collopy's (1988) distinction between executional and decisional autonomy. Decisional autonomy is the capacity to make decisions, to make personal choices and to hold personal values, even though the person may not have the ability to carry them out independently. Collopy goes on to stress the importance of making this distinction when considering older people in receipt of care and warns that most older people "will be seen as non-autonomous, even though they are still decisionally autonomous" (Collopy 1995, p.10). Just because an older person may have limited mobility or compromised health, it cannot be assumed they are intellectually impaired and their autonomy must not be measured by their lack of ability to execute decisions. As an older person becomes frailer, they are less able to execute their autonomy and without consideration of their potential to independently make choices about care, their decisional autonomy may fall by the way. It must not be assumed that the absence of physical functioning means that they have lost their ability to be autonomous. Findings to this study reinforce this executional/decisional dichotomy that is the difference between being able to make decisions about their care, whilst at the same time not being able to exercise those choices independently. Even though many of the participants had a high degree of disability and were dependent on others for very personal acts of care, they remained determined to retain some level of control over how and when that care was delivered, even though many of their efforts were thwarted, leaving them feeling helpless and without control over very basic needs. Yet at the same time, some did acquiesce and surrendered their decisional autonomy. Claire could stand or walk without support and her care package of four visits per day included washing, dressing and emptying and changing catheters and commodes. Her physical functional ability was extremely low and her executional autonomy very limited. Yet, whilst she was mentally highly capable of making decisions about care, she had yielded to the care system and allowed the carers and the organisation to determine how care was delivered. As both Sandman (2005) and Breiholtz, Snellman and Fagerberg (2013) posit, some older people in this situation who feel they have lost any form of autonomy give up on making any independent decisions out of a fear of being abandoned, and out of gratitude and loyalty to their carers. This suggests perhaps an imbalance in the cared for and carer

relationship and an element of powerlessness. Furthermore, Agich (2003) suggests that in losing self-reliance, the older person experiences feelings of worthlessness. Boyle (2005) posits that impaired autonomy can lead to depression, with mental ill-health being more prevalent in the home care setting than in residential homes. Marmot (2004) submits that autonomy has a definite effect on an older person's health and even their longevity.

6.3.4 Expressing autonomy through voicing concerns

The results of the study by Haak et al. (2007) indicate that being able to make autonomous decisions increases the quality of life. However, 8 out of 17 participants to this study were reluctant to voice concerns when care fell short of expectations. If they did complain it was done so either through a family member or they used very careful strategies, for example using a gentle voice or using humour to get the message across. However, many stifled their emotions, and stoically accepted care that failed to meet their needs. Aronson (2006) suggests that older people may keep quiet because of fear of reprisals, out of shame, pride or embarrassment, because they place the needs of others before their own or because they feel that complaining would be futile. She suggests that older people lack the energy to fight to keep control of their worlds and thus bend their needs to suit the services being delivered. In this way they struggle to retain their agency, autonomy and identity within the care environment. Findings to this study evidence poor care that went unreported with participants demonstrating feelings of embarrassment, fear and guilt, and in some instances placed the needs of carers before their own. Aronson (2006) argues that a neo-liberal discourse of self-sufficiency and independence discourages any negative evaluation of care that suggests need and dependency. She suggests that some may fear a move from home care to residential care, which, for participants to her study, was an unthinkable outcome. Furthermore, in a climate of austerity and with media stories of cutbacks to social care services, older people may feel that such rationing means that complaining would be a futile waste of energy and time. Findings to this study indicate that the greater the loss of executional autonomy, and the greater the loss of physical ability to control one's environment, the greater the reluctance to personally complain. Of course when a family member was actively involved in the care routines, they advocated on the older person's behalf, but generally those less able to care for themselves independently were reluctant to speak out due to feelings of shame, embarrassment and fear and they considered others' needs before their own. Thus participants gave up their right to determine how their care was delivered, they were relinquishing

control. As Agich (2003), Boyle (2005) and Marmot (2004) suggest this can have a detrimental effect on feelings of worth and health

6.3.5 Timings of care visits and impact on autonomy

The concept of autonomy surfaces across various themes presented in the findings chapter. However, its most predominant realisation is with regard to the timings of care, supporting findings of other researchers (Palmer et al., 2015, Sykes and Groom, 2011, Morvill and Fjordside, 2016, Byrne et al., 2012). Several participants expressed such concerns as the lateness of visits, cancellation of calls without prior notification and the cutting short of visits. The timing of calls played a significant role in older people's everyday lives particularly with regard to when help was given as this often had important implications for the decision the older person makes in relation to everyday life. The time at which the carer arrives can have an impact on whether the older person takes part in social activities such as attending the day centre or visits to family (Patmore, 2004). These are crucial for people who are typically so isolated. As time affects the person's scope for choosing both family and other social activities outside the home with attendance at the day centre most affected (Pino et al., 2013). Echoing findings in similar research studies (Palmer et al., 2015, Sykes and Groom, 2011, Morvill and Fjordside, 2016) this study reports how older people are typically expected to manage their lives around the carer's schedule, even having to go to bed whilst it was still light and then be expected to stay there until late the following morning. This is a direct affront on decisional autonomy and has a very obvious effect on personal dignity particularly when an older person is left in a soiled pad unable to get to the toilet or to clean himself. This is brought into sharp relief by the case brought in 2011 by former ballet dancer Elaine McDonald. She had suffered a stroke and was unable to use a commode without assistance. Due to impairment, she needed to urinate several times through the night and she requested a night time carer. However, she was told by her Local Authority that she must use incontinence pads, with disregard for her personal dignity and right to autonomy. This is a well-documented case which has received a great deal of public attention, yet this affront to autonomy and dignity is being experienced on a daily basis by participants to my study and those of other researchers (Sykes and Groom, 2011).

Whilst the actual time of the visit can be problematic, it is also the uncertainty of the timing of calls that causes feelings of frustration, abandonment, fear and anger (Breiholtz, Snellman and Fagerberg, 2013). Some participants to this study were disappointed with the lack of

communication about call times, expressing feelings of worthlessness, anger, disgust at the rudeness of the organisation and being frightened the visit may not happen at all and they would be left without food, medication and clean pads. However, not all participants contested late calls, again acquiescing. Some were just grateful and happy that the carer turned up at all, in spite of the impact it had on their dignity and opportunities to socially engage.

6.3.6 The importance of the home space and maintaining control

The meaning of home can be very different depending on culture, ethnicity, gender and age (Moss and Dyck, 2003) but for most it represents a place of security, safety and comfort, a place for privacy and retreat (Healey-Ogden, 2014) and a haven of physical and emotional well-being (Bender, Clune and Guruge, 2009). Daily routines are performed and personal and social identities are enacted, and for older people receiving care and spending an increasing amount of time at home, it holds significance for maintaining stability, identity and autonomy (Doyle, 2012). Typically the home is assumed to be a private space, yet when a carer regularly enters that space it becomes governed and monitored by external rules and regulations (Dyck and O'Brien, 2003). It becomes a therapeutic space where carers intrude into the privacy it once provided and the concept of home and all that it represents can be compromised. It can become institutionalised and medicalised as care equipment such as hoists, commodes, and wheelchairs are brought in to support the older person's physical needs. The home space transforms from a private space to a public space (Aronson, 2002). Healey-Ogden (2014) carried out a study of how care practices, well-being and the meaning of home within a care environment together interact. She found that older people were disturbed by new carers entering the home seeing them as strangers intruding their private space. She also observed that the carrying out of care tasks intruded into and disrupted daily routines and schedules and an older person can feel they are losing control, of their life. Furthermore she suggested that the essence of the family home can change to such a degree that the older person feels they have lost control. Findings to this study echo those of Healey-Ogden (2014), as some participants talked of feeling their home was being invaded by a string of different people, and their daily routines and rituals were disturbed by carers. Some resented new carers, seeing them as strangers particularly when they had not been previously introduced. Some told me they felt they had lost control of their home as the care they receive de-personalised their home space and it was clear they found this disturbing. Hammer (1999) even goes so far as to say that when an older person loses their sense of belonging within

their own home they experience intense psychological distress. Healey-Ogden (2014) concludes her paper with a recommendation that care organisations do not create mini-institutions in homes focusing purely on meeting physical need, and that their focus should also be on the significance the home space represents in promoting the individual's sense of autonomy. Findings to this study also evidence how vital it is that carers understand how, when they treat the home as purely a place of work to execute a list of tasks, this has the potential to have a detrimental psychological effect on the older person.

6.3.7 Autonomy is relational

The distinction between executional and decisional autonomy proves invaluable within this care setting. This is particularly true when we appreciate and understand that loss of functional ability should not restrict an individual's decisional autonomy. Losing one's independence should not mean losing one's autonomy, or their opportunity to exercise choice about the care that they receive. However, feminists take the autonomy concept even further and argue against its more traditional liberal interpretation. They rail against the emphasis on the independent rational and self-governing agent who experiences freedom from interference by others (Mackenzie & Stoljar, 2000) and they challenge the idea that autonomy is something to achieve and a goal to be universally aspired to (Fine and Glendinning, 2005). They assert that this is a view that promotes negative rights, that is the right to the non-interference of others and that dependence is seen as "tantamount to a degrading submission" (Agich, 2003, p.7). Agich argues that older people who experience frailty and disability are necessarily dependent on others for their care, and when their dependence is seen in such a negative light this has a detrimental effect on their well-being. Sherwin and Winsby (2011) postulate that this counter-dependent view of autonomy can lead to discrimination and oppression and a diminished sense of self-worth. Instead, the feminists argue that autonomy is better characterized as involving networks of relationships and interdependencies. An individual is never wholly independent but rather located within interpersonal relationships and broader social environments which are pervasively influential. Whilst acknowledging and supporting the concept of autonomy, they have reconceptualised it as being socially constructed and deeply embedded within a network of relationships. The theory of relational autonomy posits that autonomy is realised within and because of relationships, or as Donchin quotes "Any tenable conception of personal autonomy is bound to be subject-centered; but a social conception that is relational will take into account the need for a network of personal

relationships to develop and sustain competencies necessary to act as self-determining, responsible agents” (2002, p.192).

Perkins et al. (2012) suggest that this approach encourages one to look at how conditions at the macro, meso and micro levels might promote or diminish an individual’s autonomy, that is the cultural or societal level (macro), the systems level including institutional frames and routines (meso) and at the level of the relationship that exists at the point of interaction between the carer and the older person (micro). Looking through these lenses will help to shine a light on conditions that may exist within each of these environments that might threaten autonomy. Recognising that any definition of autonomy must be context dependent, Agich (2003) was keen to look at the “concrete manifestations” (p.11) of actual autonomy within the care setting, looking at the interactions and structures of care across these levels. My research supports this approach and it becomes useful when we look at issues such as the timing of calls and the regularity of carers. When carers are late and an older person’s decisional autonomy is threatened and they feel abandoned and undignified, it is to be examined at each of the micro, meso and macro levels. That is, how does the carer respond when he turns up late, what systems are in place within the organisation to manage the times of calls and to reduce the number of late calls, and how does society view the older person sitting in the chair waiting for a carer to visit? The latter point touches on the issue of possible ageism and discrimination, and the possible societal assumption that being disabled or infirm is a natural and inevitable part of getting older. However, at the meso level, I evidence that there are institutional frames and routines that directly threaten an older person’s autonomy and thus dignity, for example, when Lionel was left in bed in an incontinence pad until 10 am unable to get to the toilet since the previous evening. There seemed to be no management procedures in place to recognise Lionel’s plight and divert another carer to his needs. The evidence presented across findings indicates that autonomy was for some dependent on the relationship between the older person and the care organisation’s management, procedures and practices. Autonomy is to be understood at the direct interactional level but also more pertinently at the organisational level, and in addition at the political and societal level, to explore whether there is congruence between assessment of need and the delivery of the care package, including the allocation of care time. Resources and staffing ratios are difficult under current funding conditions, but understanding autonomy using a relational approach will help care management and care staff to recognise how the care they deliver enhances feelings of control and dignity (Sherwin and Winsby, 2011).

6.3.8 Task-based care and effect on autonomy

The implementation of outcome-focused care has been slow with Local Authorities seeing the task-based approach as their biggest obstacle (Lucas and Carr-West, 2012). In their survey, Lucas and Carr-West (2012) received responses from 210 Local Authority officials and found that 35% of those officials reported outcome-focused only being used to a 'limited degree'. Yet task-based care has been criticised for being inflexible and for not being able to promote relational care due to inconsistency of care staff (Equality and Human Rights Commission, 2011, Francis and Netten, 2004, Byrne et al., 2012). In the 90's, managerialism and the commodification of care meant that assessments for domiciliary care were very much needs-led with the identification of standardised tasks to be delivered that could be neatly packaged into easily marketable time slots. The emphasis was very much on supporting purely physical activities of daily living in order to maintain the individual within their own home whenever possible. (Ugwumadu, 2011). This approach to care delivery had little space for meeting the psycho-social needs of older people, needs that were not only difficult to define but costly and complicated to meet (Aronson, 2002). Manthorpe et al. (2008) established, through their research into domiciliary care across various localities, that older people found the task-based model of care reductionist and impersonal. Byrne et al.'s study (2012) found that older people felt a lack of identity, individuality, and uniqueness when the focus of care was on the tasks to be completed. Equality and Human Rights Commission (2011) report that when carers are allocated tight narrow time bands for carrying out activities such as dressing, bathing and preparing meals, there is no room for flexibility to meet individual needs and no room for service-user choice or autonomy. Francis and Netten (2004) and Byrne et al. (2012) cite examples of non-negotiable care where carers are unable or unwilling to deviate from the care plan to help with tasks such as hanging out washing, to provide help with filling out forms or arranging GP appointments as they are 'not on the job sheet'. When challenged, service providers blame uncompromising, inflexible and cumbersome social services contracts. Sykes and Groom (2011) cite older people's experiences of carers rushing through a list of jobs with little communication as though the older person was being processed rather than being cared for. Gethin-Jones (2012a) and Equality and Human Rights Commission (2012) both report examples of inflexible care that affronts dignity and denies autonomy. On the other hand Byrne et al., (2012) evidence carers who work within task-centred methods being flexible and negotiable. In spite of the rules about the tasks to be performed, carers would deviate from the care plan to meet other needs,

hiding additional tasks from the care organisation. My research provides some examples of care that is prescriptive and inflexible. Some struggled to have their needs reassessed so that the care packages could be adjusted to better suit their needs both in terms of how care was delivered and at what times.

6.3.9 Outcome-focused care, relationship and autonomy

The building of relationships very much depends on consistency of carer and this has proved so important to many of the participants to this study. Yet, Gethin-Jones (2012b) suggests that the task-based model of care, due its very nature, does little to promote the relationship between carer and cared-for. At the organisational level, Francis and Netten (2004) claim that managers have difficulties in recruiting and retaining staff and struggle to cover unauthorised and unexpected absence. They struggle to maintain the continuity so needed by older people with high levels of staff-turnover and the frequent juggling of rotas to cover absences. At the interactional level, Gethin-Jones (2012b) suggests that relationship is impeded by care that rigidly sticks to task lists, allowing little room for negotiation, with carers feeling rushed and under pressure to complete a challenging job sheet across their day. Recall Susan's carer's comment that she liked visiting Susan as she could get away in less than the allocated time and rush off to the next person needing care. This upset Susan greatly and any opportunity for relationship building with this carer was lost.

Gethin-Jones (2012b) suggests, in his research which compares the task-based and outcomes-focused models of care, that an outcomes approach better promotes relationship and autonomy, provides greater flexibility in the way in which care is delivered and provides more opportunity for social engagement. With the introduction of the 2014 Care Act has been a focus on the assessment to identify not simply the care and support needs but, more pertinently, the outcomes the individual is looking to achieve to maintain or improve their wellbeing and how care and support might help in achieving those outcomes. It focuses less on the tasks but more on a person-centred care delivery that improves overall outcomes. Glendinning et al. elucidate "Outcomes are defined as the impact, effect or consequences of a service or policy. Outcome-focused services are therefore those that meet the goals, aspirations or priorities of individual services users" (2008, p.55). Gethin-Jones (2012a) gives examples of outcome-focused care, such as banking up of hours so that the carer can assist the older person in taking his dog for a walk, or using banked hours to go to the pub to watch a game of football. One older lady was worried that her husband's grave was untidy, so the

carer, using outcome-focused care, brought along some gardening tools to tidy it up. Generally the participants to his study who received outcome-focused care reported greater subjective well-being, feeling less isolated and lonely, and feeling as though care is done with them, rather than to them. He also suggests that there is greater continuity of staff when outcome-focused care is employed, although he does suggest this is because of management deciding to create small teams of carers to manage the outcomes-focused pilot.

It was impossible for me to ascertain for each participant whether the care provider was delivering care using the outcomes-focused model or the task-based model as I did not liaise directly with organisations themselves. However, there did seem to be difference in the style of delivery across participants. Those who were physically more capable and who did not need personal care were more able to choose how they wish their care to be delivered and what activity they wanted to engage with. They seemed to have greater control over their everyday lives and service delivery was more akin to the outcome-focused style of care delivery that Gethin-Jones witnessed (2012a). Yet the care for those who had greater loss of physical functioning was very much centred on the completion of sometimes very personal tasks that were lengthy (and thus expensive) to perform. For some it was essential for care to meet their basic physical needs and this meant up to 3 or 4 hours of care per day. There was never going to be any improvement in their physical functioning, it would only deteriorate, and so aiming for an outcome of greater independence was futile. Yet some of these participants did express feelings of isolation and loneliness, and would have appreciated the opportunity to be more socially engaged, a target clearly identified in the outcome-focused model.

Against the backdrop of the current austerity measures being imposed on social care providers, Glendinning et al. (2008) question whether additional budgets are allocated for those who rely so heavily on tasks that meet their basic physical needs in order to promote independence and greater social engagement. The authors report that in some instances where outcome-focused services were being delivered to the old and frail, the focus was more on physical maintenance than on social or quality of life outcomes

Whilst the proponents of outcome-focused care suggest that this model promotes relationship- building, consistency of staff, greater flexibility and greater autonomy, Gethin-Jones (2012b) does concede that any improvements with regard to quality of life and meeting outcomes was not necessarily down to the outcome-focused model itself, but rather by the

process of delivery. This suggests that the way in which care is delivered could be more significant than the model chosen, that is the experience of using services including feeling valued and respected, being treated as an individual and having control over how and when services are provided. These are outcomes that have been clearly supported across literature (Francis and Netten, 2002, Qureshi and Henwood, 2000). I have demonstrated through my research that many of the participants' concerns were centred around the way in which care was delivered rather than the acts of care themselves, including reliability of services, communication between themselves and the carer and the care organisation, the importance of consistency of carer and being shown care, concern and respect.

The aims and objectives of the outcomes-focused model are commendable in that they place the older person at the centre of care, yet I suggest that task-based care can be delivered in such a way that also meets the concerns of older people, ensuring as much as possible that they see the same carer and that care is delivered in a respectful way that promotes dignity and autonomy. Communication skills are paramount. Some of the participants spoke of carers not using their correct name, of rushing through tasks, with no eye contact, of arriving at the home and jumping straight into care tasks without a proper introduction. For those older people who depend on several hours of care each day, who are isolated and for whom the carer represents the only social contact, the way in which care is delivered is fundamental

In the following chapter I will suggest the implications for practice, make recommendations for further research, discuss the strengths and limitations of the research and reflect on my experience as a researcher.

Chapter 7

Conclusion

I began this study with the following research questions:

1. How are domiciliary care practices experienced by older people?
2. To what extent is domiciliary care delivered in a way that considers sense of self?
3. How do care practices link to autonomy and how important is this for sense of self?

At the centre of these questions is the concept of the self and I acknowledge, through my conceptual framework, that there are two aspects to this uniqueness, namely self and identity. Erikson's life stage theory (1982) and social constructionism and role theory (Stryker 1968) have provided a unique theoretical lens through which to interpret such concepts and make a contribution to the knowledge with regard to domiciliary care and its interaction with self.

The more introspective version of self, that Erikson espouses, is that which has developed along life's journey, through the resolution of the challenges and conflicts of life stages. Overcoming these stages allows the person to emerge with a feeling of unity with oneself, good judgment and a greater capacity for success. Identity, on the other hand, is socially constructed through roles that are enacted, with each role bringing forth a role identity. Identities are developed and maintained within the role relationships, and through labelling ourselves as belonging to particular social categories, we build our own self conceptions and attribute meaning to ourselves.

Looking through the lens of Erikson's life stage theory, this research reveals that good care considers the uniqueness of the older person and the experiences they bring to care. For some, past successes in coping with challenges have increased their ability to cope with being cared for professionally, in older age. Furthermore, individual and personal wants, needs, values, preferences, their very selves, affect how they experience domiciliary care. Findings have also highlighted the unique forms of coping with getting older that have been employed by participants to this study. Yet this research and others previously, has highlighted the tendency of some domiciliary care providers to homogenise older people. This study also evidences that some older people enter into a more reflective, spiritual stage and that their

wants and needs change as they transcend everyday limitations and concentrate on a more universal understanding of life (Tornstam, 1996).

From the social constructionist position, this research reveals that relationship is a fundamental aspect of good care, and the way in which the carer and cared-for roles are enacted, makes a significant contribution to feelings of satisfaction with care. Relational, person-centred care, delivered by consistent, regular carers, seems to be the most successful, with many of the participants speaking about the positivity they feel when they have developed a trusting and supportive relationship with their carers. Additionally they speak about the impact this has on their sense of safety and security. For some the carer has become like a family member and this has had positive effects in terms of not only familiarity and friendship but also the regular carer's awareness, understanding and management of deteriorating health.

Furthermore, this research reveals that this relationship also has the potential to positively influence individual autonomy. As physical functioning diminishes, so executional autonomy is compromised. When an older person's health deteriorates to such a degree that they need support with acts of personal care, they become increasingly unable to personally execute the decisions they make about that care. However, in this study I found that, in some cases, this is further exacerbated when they are deprived of decisional autonomy, and are unable to make decisions about how care is delivered. For some, this could have devastating effects. Yet when regular carers are familiar with the range of needs of the older person, they are more likely to be able to deliver care in such a way that decisional autonomy is not compromised.

Thus this study offers important insights into how domiciliary care interacts with self. Firstly, there is a need for carers to focus on the uniqueness of self and to understand the value of treating each older person as an individual. Secondly, the relationship between carer and cared-for, built on regularity and consistency, increases feelings of satisfaction with care. Thirdly, older people value autonomy, even when they are physically unable to execute it for themselves. These insights have important implications for both practice and for further research.

Implications for practice

This study delivers important messages to care practitioners and, on the basis of the findings, a number of recommendations are made to improve the provision of domiciliary care to older people

With regard to how carers view the ageing process and hence how they relate to older people, care should not be constructed and delivered using myths and stereotypes of what it is to be older. In order to deliver individualised and person-centred care, it is necessary for carers to recognise and understand the different ways in which people manage and adapt to growing older and to acknowledge their unique experiences, images and attitudes. Assumptions should not be made about what it is like to get older and to need care at home. For example, carers should be trained to recognise the signs of gerotranscendence, and know how to respond within the caring dynamic. Katz (2000) argues that activity theory is the dominant paradigm when caring for older people and carers can feel a duty to engage the older person in activity with little regard for their own wishes. However, knowledge of the theory of gerotranscendence may support carers to understand that passivity and isolationism may be preferred as the older person enters into a spiritual and reflective stage in their lives (Wadensten and Carlsson, 2003).

Carers should also develop awareness and understanding of the value of the biographical approach, and get to know the older person through a written narrative of their lives, their personal histories, preferences, likes, dislikes, strengths, vulnerabilities, values etc. and care plans should be developed and delivered that reflect the older person's unique needs and priorities. Furthermore, Clarke et al. (2003) evidence that the biographical approach has the potential to positively influence carers' attitudes towards older people as they gather information about their life's journey and recognise the uniqueness of the older person. Carers have the opportunity to gain a very different picture from that which is formed behind the mask of ageing (Hepworth, 1991).

Findings of this study strongly highlight the importance of the relationship between the carer and the older person within the context of home care. Isolation and loneliness was evident and carers should recognise the importance of the key role they play when often they are the only person that the older person may see from one day to the next. Loneliness and isolation are very different concepts. Whilst isolation refers to separation from community engagement

and loss of social or familial contact, loneliness is a more subjective feeling brought on by an imbalance between one's access to social networks and the desire for social interaction (Routasalo et al., 2006). Yet some participants to this study experienced both and the carers' visits were significant and positive aspects of their lives. Furthermore, this study's findings also evidence that the attendance of consistent carers allowed the development of valued relationships. Care organisations should ensure that carers are consistently allocated to older people so that an understanding and rapport can develop.

Autonomy was a recurring theme across the findings and carers should acknowledge and understand the difference between executional autonomy and decisional autonomy. The absence of functional ability to exercise choice does not necessarily mean that the capacity to make decisions is also lost. Carers restrict the older person's autonomy by making choices on their behalf, yet maintaining decisional autonomy is fundamental to feelings of well-being (Boyle, 2005). It is a recommendation that each older person should be supported to make meaningful choices and decisions within the care context

The findings of this study evidence that some older people are very reluctant to make complaints, often for fear of repercussion and the worry that they might be placing their care at risk by making a formal complaint. Care organisations should develop a more secure, confidential and easily accessible complaints system that facilitates an easier dialogue and flow of information between older people and care providers. The system should ensure the experience is not stressful or threatening and causes no disruption to care.

A common complaint across the study was that carers were often late or did not show up at all, without prior notice. The consequential lack of control and choice can undermine their personal autonomy. There should be improved communication with older people about possible late calls and cancellation of calls and also about any change of carer.

Some participants to this study spoke about how their home space had lost its essence as a home and that this threatened their feeling of autonomy. Furthermore, the caregiver's entry into the home can challenge personal identity (Dyck, et al., 2005). Care organisations should ensure that the older person maintains control over their home environment and that they are consulted about any potential changes, for example with regard to equipment location and any such changes should take the least restrictive and intrusive approach. Carers should be

encouraged to respect and maintain the integrity of the home and understand and support the meaning that home holds for the older person.

Some participants spoke of inflexible services where carers adopted a rigid approach to care, delivering tasks without any consideration of individual wishes or any change in circumstances. There was evidence of an over-emphasis on a task-centred approach allowing little negotiation with the older person. There should be a greater focus on outcomes within the care setting and a greater degree of flexibility around tasks that need to be executed with periodic reviews of any change of circumstances that bring about a change in needs.

Implications for further research

Further studies are recommended that focus on the carer's perspective of their practice and to understand how they negotiate the pressures they might experience when delivering care, for example, with regard to the management of rotas, timings of calls and switching of staff. Policy makers and service providers should be presented with the findings of such research.

It is also recommended that a study should be carried out with care organisations in order to understand recruitment practices and training programmes and how they can be developed to promote empathic, supportive care that respects the self.

Further research should also focus on the pressures on care organisations and how these affect the care that is delivered and at the same time, explore organisational awareness of how procedures and practices directly affect older people, together with the possible existing barriers to implementing effective changes such as those that are suggested herein.

The number of participants to this study was 17 and all but three of those were women. Whilst the findings do not identify any significant difference between the male and female responses, I recommend that a similar study be carried out with more male participants in order to establish whether there are any differences in their experiences of care and interaction with self.

Strengths and Limitations of the research

A significant strength of this study is that it hears directly the older person's perspective on how they feel when care either promotes or undermines their sense of individuality. Furthermore, the study has been carried out within the context of their own home. Whilst for

many participants, this was the most convenient option since they were unable to easily transport to a neutral location, this has not been purely a logistical decision. Interviewing participants in their own home has the potential to allow them to talk more freely in their own space and for them to feel more comfortable, which can generate a sense of intimacy and friendliness. It also afforded the opportunity to gain first hand insight into the environment in which care takes place and to construct a better understanding of their lived reality. The value of this study lies in part, in building knowledge from this unique perspective. This enabled invaluable insights into the emotional and physical needs of older people, useful to practitioners of domiciliary care.

The research methodology has proved invaluable. The biographical-narrative stage of the enquiry not only gave the opportunity to hear participants' stories about getting older and the care they receive, but it also facilitated a level of relationship. It was through this interaction that a level of trust, familiarity and understanding was borne. The diary, on the other hand, gave participants the opportunity to express their own thoughts and feelings about incidents of care in their own space and time. It also acknowledged the limitations caused by difficulties in recall often experienced by the older population. The data collection method entailed three visits and this helped to develop rapport between researcher and participant. This proved invaluable when it came to the follow-up interview. It was at this stage that I explored the issues that had been raised in the diary and mapped them to the narrative, to reflect on how some instances of care reconciled with their individual selves, their idiosyncratic likes, dislikes, needs and values.

A limitation of this study is that the sample has limited diversity in terms of ethnicity and gender. Some qualitative studies aim to gain intentionally heterogeneous samples, for example grounded theory uses the maximum variation sampling technique (Strauss and Corbin, 1998). It is more likely that commonality found across a heterogeneous sample can claim generalizability (Engel and Schutt, 2014). However, many qualitative methods, and in particular those used within the narrative methodology rarely seek generalizability (Waltz et al., 2010). Indeed, I did not set out to achieve generalizability or draw broad inferences, but sought to generate new theoretical insights through rich, contextualized understanding, in order to make recommendations to practitioners and policy makers for the improvement of domiciliary care services. However, as I point out in the methodology chapter 4, I did find it difficult to engage men to the study, and hence my earlier recommendation that a further

similar study should try to recruit men to establish whether their experiences of care with regard to respect for self is different from that of women.

Whilst I was able to reach many of the older people through day centres, and even though I advertised in magazines, I struggled to reach those who were unable to leave their homes due to frailty and poor physical functioning. Often this group of older people are excluded from studies (Hoban et al., 2011) and yet with the growing older population their voice needs to be heard.

Contribution to knowledge

In summary, this research provides an important contribution to both practice and methodological knowledge.

Form a practice perspective, the study can guide care practitioners to a better understanding of the ageing process and the importance of individualised and person-centred care that respects heterogeneity. Furthermore, it explores the value of the biographical approach when working with older people, the huge importance older people place in the relationship they hold with their carers at home and how this relationship can mediate against feelings of loneliness and isolation. Much can be learned by those responsible for staff rotas from those participants who speak so strongly about the regularity of the carer and how it can help to forge strong meaningful relationships promoting feelings of autonomy within the home.

However, the data collection method of biographical-narrative/diary/follow-up interview used within this study also makes an important contribution to the methodology of researching care and old age. Whilst there is a paucity of research into the domiciliary care of older people, there are very few studies that place the older person at the heart of the study within the context of the home. Furthermore, the three stage data collection method provided very rich data, presented the opportunity to maximise validity through the cycles of data verification and facilitated relationship-building that enhanced the interpretation of the data.

Reflection

As I come to the end of this study I am beginning to feel a strange combination of relief and loss. Relief because that this four year, often arduous, exhausting and challenging journey is

approaching its final destination and new exciting challenges await. However, I also feel a sense of loss as I prepare to turn the last page of this creation of mine. Yet I take comfort in that for me, this journey has been more than just a happening, it has been a process of transformation and my life experience has taught me that, through reflection, I will reap the richest learning.

As I look at how I have evolved as a writer, reader, researcher and practitioner, and more holistically as a person in environment, and I tell the reader about my thoughts and feelings I feel a connection to the narrative that I promote through this study. I place myself in a somewhat similar narrator position to that of my participants as I reflect on the story of my journey as researcher. What would I tell about the ups and downs of this part of my life? I know I would want to project the most favourable positive version of events, putting myself as researcher in the best light. For sure my critical thinking has evolved as I have engaged with literature at a far deeper level than before, and I have project-managed the entire process with my normal focus-driven determination. On the other hand, would I want to launder in public the dirtiest, messiest experiences that often brought me to my knees with frustration and exhaustion? There have been times when I felt fraudulent in my role as Doctoral researcher, with my self-esteem plummeting to levels difficult for myself and others and, note worthily, my supervisors to fathom.

Through this reflection I appreciate and value, even more, the contribution of the older people that accompanied me along this journey. As I reflect back on how participants recounted their stories of their lives past and present, I realise how much they courageously gave of their selves. It is this realisation that drives my passion to take this learning to the next stage in order to influence, encourage and support home care practice so that they might acknowledge and appreciate the uniqueness of each and every older person.

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APPENDIX 1

Ethical Approval



Anglia Ruskin
University

Cambridge Chelmsford Peterborough

Ref: PL/pmx/SH-13/40
Enquiries: Pamela Maxwell
Direct Line: 01245 684820
Date: 04 December 2013

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Suzanne Hughes

Dear Suzanne,

Re: Application for Ethical Approval

Project Number: 13/040

Project Title: An exploration of how domiciliary care services interact with an older person's sense of self.

Principal Investigator: Suzanne Hughes

Thank you for your application for ethical approval which was considered by the Faculty (of Health, Social Care & Education) Research Ethics Panel (FREP), at its meeting on 13 November 2013.

I am pleased to inform you that your research proposal has been approved by the Faculty Research Ethics Panel under the terms of Anglia Ruskin University's *Policy and Code of Practice for the Conduct of Research with Human Participants*, subject to you providing a DBS form which we feel is required. Approval is for a period of one year from 13 November 2013.

It was agreed that your research was a very thorough application.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Policy and Code of Practice for Research with Human Participants and specifically:

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these changes until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.

- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP Secretary copies of this documentation.
- Any laws of the country where you are carrying the research out (if these conflict with any aspects of the ethical approval given, please notify FREP prior to starting the research).
- Any professional codes of conduct relating to research or research or requirements from your funding body (please note that for externally funded research, a project risk assessment must have been carried out prior to starting the research).
- Notifying the FREP Secretary when your study has ended.

Information about the above can be obtained on our website at:

<http://web.anglia.ac.uk/anet/rdcs/ethics/index.phtml/>

Please also note that your research may be subject to random monitoring by the Committee.

Please be advised that, if your research has not been completed within the year, you will need to apply to our Faculty Research Ethics Panel for an extension of ethics approval prior to the date your approval expires. The procedure for this can also be found on the above website.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely,



Dr Paulette Luff

For the Faculty (of Health, Social Care & Education) Research Ethics Panel

T: 0845 196 3544

E: paulette.luff@anglia.ac.uk

cc: Sarah Burch (Supervisor)
Beverley Pascoe (RESC Secretary)

APPENDIX 2

Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Dear Participant,

It is with great pleasure that I invite you to take part in the study:

“Domiciliary care, self and older age”

I am a student PhD researcher from the Faculty of Health, Social Care and Education at Anglia Ruskin University, Chelmsford

What is this study about and why am I doing it?

I will talk to older people who are in receipt of care, in their own homes, about the care they receive so that I may be able to answer the following questions:

- How are domiciliary care practices experienced by older people?
- To what extent is domiciliary care delivered in a way that considers sense of self?
- How do care practices link to autonomy and how important is this for sense of self?

I hope that this information may then be passed on to care providers, social workers and other professionals to better understand the perspectives of older people during care and support, and to inspire new strategies for care provision.

Who is being invited to take part?

I plan to work with approximately 30 older people, from the age of 65, who are in receipt of domiciliary care services.

Why should you get involved?

Your experiences as a user of domiciliary care services will contribute towards a better understanding of the how care practices affect an older people. The findings of this study may enable the improvement of domiciliary care services.

What will happen if you agree to take part?

This study will start approximately January 2014 but your involvement could happen anytime between January and August to suit you. Should you decide to take part in the study, I will ask you to sign and date a consent form. The first interview date will be arranged at a time to suit you.

➤ The first interview

First of all I will visit you at home to talk with you about your personal history, how you started to receive care and how you have felt about it. The interview will last approximately 1 hour but you can stop it at any time if you do not want to continue, or feel unable to continue. I will ask you if it is OK for me to record the interview so that I don't forget anything you say.

I will then show you the diary and explain how to complete it.

➤ Completing the diary

I will give you a 2 week diary where you can record any thoughts and feelings around the care you receive. It will have some instructions written on the first page to help you. I will ask you to not use any names in the diary so that everyone remains anonymous. If you are worried about writing something down, but feel you would like to share it, I will ask you to mark that day with an asterisk * so that we can talk about it together.

I will come and collect the diaries at the end of the 2 weeks.

➤ **The second interview**

After I have looked at the diaries I will return approximately a week later to talk with you about the diaries and the events, and the thoughts and feelings you have written down. As before, the interview will last approximately 1 hour but you can stop it at any time if you do not want to continue, or feel unable to continue. I will ask you again if it is OK for me to record the interview so that I don't forget anything you say.

Once this second interview is complete, approximately 5 weeks after the first interview, your involvement will finish. However, I can keep you informed of the progress of the research if this is what you would like.

What will happen at the end of the study?

The findings from the interviews and the diaries will be discussed in a thesis /dissertation and may be presented to professionals and social workers at conferences and in publications. They may also be used in discussions with care providers to present new knowledge. However, your name, or the names of any people you talk about, will not be written down at all, and the information you give me will remain strictly confidential.

What if I don't want to take part?

It is OK if you decide you do not want to take part. This is completely voluntary, and I only want you to be involved if you are happy to do so. I will not try to persuade you if you decide it isn't for you.

Can I stop taking part at any time?

You can stop at any time during the study. You do not have to explain to anyone why you choose to stop and no one will ask you why you no longer wish to be involved. You can either tell me in person or write to me, or if you prefer you can tell either of my supervisors Dr Sarah Burch or Dr Roxana Anghel (see their contact details below). They will pass this information on to me without giving me your reason.

You can also choose to take a break during the study, again without explanation, and I will respect your wishes. I will reschedule any sessions, if that is what you wish, at a time to suit you.

Are there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety?

It is anticipated there will be minimal risk to you becoming upset. If this does occur, I will request that support is provided. In the event of poor practice being highlighted during the study, this will be discussed with you and if appropriate referred to the relevant care organisation in line with their safeguarding policies and procedures. If undertaking the study gives you any problems or concerns, or if you would like to have more information and clarification, please do not hesitate to contact me.

Are any benefits from taking part?

Your experiences as a user of domiciliary care services will contribute towards a better understanding of the how care practices affect an older person. The findings of this study may enable the improvement of domiciliary care services.

What will happen to the information?

All interviews will be recorded and then written down/transcribed. After this, the recordings will be deleted. Your name will not be written down in the transcripts, as I will use an identity number for you, to make sure you remain anonymous.

The diaries will also just have your identity number inside, and I will ask you to not use any names when you are writing the diary so that other people also remain anonymous.

During the study, the interview transcripts and the diaries will be stored in a locked cupboard and only accessed by myself and my supervisors. Once the study is finished, the future storage of this information will be discussed with you and destroyed if you so wish.

Any information about you within the final report or any other papers or journals will have your name and address removed so that you cannot be recognised. Your rights

to confidentiality will be respected at all times in accordance with the Data Protection Act 1998.

Thank you for taking the time to read this!

If you would like to participate or you have any questions please contact me:

Sue Hughes:

E-mail: [suzanne.hughes2@student\(anglia.ac.uk\)](mailto:suzanne.hughes2@student(anglia.ac.uk))

Tel:07578869384

Supervisors:

Dr Sarah Burch

Email: [Burch, Sarah \(sarah.burch\(anglia.ac.uk\)\)](mailto:sarah.burch(anglia.ac.uk))

Dr Roxana Anghel

Email: [Anghel, Roxana \(Roxana.Angel\(anglia.ac.uk\)\)](mailto:Roxana.Angel(anglia.ac.uk))

YOU WILL BE GIVEN A COPY OF THIS TO KEEP, TOGETHER WITH A COPY OF YOUR CONSENT FORM

APPENDIX 3

Participant Consent Form

PARTICIPANT CONSENT FORM

NAME OF PARTICIPANT:

Title of the project:

Domiciliary care, self and older age

Main investigator and contact details:

For further information please contact Suzanne Hughes
e-mail suzanne.hughes2@student.anglia.ac.uk

Supervisors:

Dr S.Burch

Email: Burch, Sarah (sarah.burch@anglia.ac.uk)

Dr R. Anghel

Email: Anghel, Roxana (Roxana.Anghel@anglia.ac.uk)

Members of the research team:

Suzanne Hughes

1. I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.
2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.
3. I have been informed that the confidentiality of the information I provide will be safeguarded.
4. I am free to ask any questions at any time before and during the study.
5. I have been provided with a copy of this form and the Participant Information Sheet.
6. I understand that any interviews with myself will be recorded.

Data Protection: I agree to the University¹ processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*

Name of participant

(print).....Signed.....Date.....

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

¹ "The University" includes Anglia Ruskin University and its partner colleges

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project:

An exploration of how domiciliary care services interact with an older person's sense of self.

I WISH TO WITHDRAW FROM THIS STUDY

Signed: _____ Date: _____

APPENDIX 4A

Narrative Format

Biographical- Narrative Interview

- Lightly structured depth interview following the Biographical Narrative Interpretive method (BNIP) (Wengraf, 2001)
- So one initial single question aimed at inducing narrative, followed by narrative questions on mentioned topics and further questions relevant to the interests and theories of the research subject.
- Minimalist interviewer intervention
- Active listening

Possible initial question:

“How have things changed for you since you have got older?”

Wengraf (2001) *Qualitative Research Interviewing: Biographic Narrative and Semi-Structured Methods* London: Sage.

APPENDIX 4B

Diary Format

The Diary Format

- Large hardback notebook
- Marked up with day1 /day2/day3 etc. on top of page for 14 days
- Several pages for each day (tabbed to days so easy to find right day) although instructions should state that there is no minimum or maximum word requirement.
- Suggestion that bullet points will be acceptable if the participant does not wish to write in long-hand.
- Suggestion that if a participant is unable to write in the diary then an alternative can be made available e.g. a Dictaphone.
- Present a guide at front of book with some instructions and prompts e.g.
 - Explain any aspect of care that you think is important
 - What happened and when and what was involved?
 - Please reflect your thoughts and feelings around these events
- Instructions also given verbally at the end of the stage1 interview before commencement of the diary stage

APPENDIX 4C

Follow-up Interview Format

Interview Schedule

The interview schedule will very much be determined by the dairy entries and the narrative biographic interview but will focus on the entries and how they relate back to the issues discussed in the first interview.

Examples of questions that may be asked are:

1. What has been your experience of this diary collection period?
2. Do you feel you have control over how care is delivered?
3. Do you believe you are treated in a way that respects your dignity?
4. How would you change the way care is delivered if you were able?

APPENDIX 5A

Thematic Analysis for Susan's Biographical-Narrative

Thematic Analysis for Susan's Biographical-Narrative

P9 NARRATIVE	P9's husband: Yes, well morning is three quarters of an hour, lunch time is half an hour and evening is half an hour and sometimes they might finish a bit earlier and if I'm here I usually say 'you can go if you want to' but usually they stay to have a little chat which is fine, but <P9> gets on with the majority of them she sees but <carer> is the only one she'll have intimate conversations with	Nodes\\AUTONOMY\model of care\going beyond the task list
P9 NARRATIVE	she said 'you've got to call the doctor if you don't I will' and that was that Interviewer: So it was <carer> who confirmed that something was wrong P9's husband: She knew straight away, she said 'I'm not interested if she wants to go but she is', she used to drive an ambulance she was a paramedic and she knows her stuff and that's the difference	Nodes\\AUTONOMY\model of care\going beyond the task list
P9 NARRATIVE	So how often do you have strangers coming in? Is it very often? P9: On a Tuesday and on a night time I don't know who's coming in, all they do at night time is cream my legs and back you know Interviewer: So having strangers coming in and doing very personal things for you, that disturbs you does it? P9: Yeah	Nodes\\AUTONOMY\Regularity of carer
P9 NARRATIVE	she said 'you've got to call the doctor if you don't I will' and that was that Interviewer: So it was <carer> who confirmed that something was wrong P9's husband: She knew straight away, she said 'I'm not interested if she wants to go but she is', she used to drive an ambulance she was a paramedic and she knows her stuff and that's the difference	Nodes\\AUTONOMY\Regularity of carer
P9 NARRATIVE	So she's not precious with you P9: She doesn't want to hurt me Interviewer: But she's not so gentle that it's silly P9: No	Nodes\\AUTONOMY\Regularity of carer
P9 NARRATIVE	Well funny enough we get a couple coming in and that but I've said to <P9> 'are you okay with it?' and she's said yes, and I've hung around while they've been here and she's never been uncomfortable with it, usually what I do is take <dog> out because they're here for half an hour Interviewer: SO that's gives you the chance to take the dog out while someone is here P9's husband: That's right, but I don't if there's a stranger	Nodes\\AUTONOMY\Regularity of carer

P9 NARRATIVE	<p>And how do you feel about your carers when they come in?</p> <p>P9: Alright some of them are alright</p> <p>Interviewer: Yeah, <carer> is very good I hear?</p> <p>P9: Yes she's very good</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Okay, no that's fantastic no so <carer> is the one <P9> has struck up a great friendship with and she's close to her, I mean we don't have a completion over these things</p> <p>Interviewer: No, but she is someone else very important in <P9's> world, and she does personal care for her?</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>P9: No she's not gentle</p> <p>P9's husband: What do you mean? She doesn't knock you about</p> <p>P9: No she doesn't but she's not gentle I wouldn't like her to be gentle</p> <p>Interviewer: That's interesting, why's that?</p> <p>P9: Because I know I have to be dried and washed</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Do you have a conversation with them or?</p> <p>P9: Not if I can help it</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>But I guess what you're saying is when it's someone you don't know you find it difficult?</p> <p>P9: Yeah, because I won't let them shower me the strangers</p> <p>Interviewer: You don't like them to do that?</p> <p>P9: No</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>I don't mind some of them, some of them I don't like, because they come in on my privacy and I don't like that</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Yes it's fortunate you've got <carer> coming in</p> <p>P9: Yes she's an angel she is</p> <p>Interviewer: What's brilliant about <carer>? If you were to say one thing that's fantastic about her being your carer what would it be?</p> <p>P9: She's an angel, don't let her hear me telling you that <laughter></p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>I think I'd feel like that too, what could they do to make you feel better about that? How could they be that would make you feel less that way?</p> <p>P9: Well I don't know, introducing themselves wouldn't be too bad</p> <p>Interviewer: Oh do they not do that?</p> <p>P9: No, and I don't know who they are, the strangers who come in, some I know like <carer> I know I like her</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>That's right</p> <p>Interviewer: Does it cause tension?</p> <p>P9: Yeah it does because I don't talk to them and they don't talk to me</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Is it that they're here and they don't talk, neither of you talk to each other?</p> <p>P9: Yeah</p> <p>Interviewer: Is that what it's like when anyone comes who isn't <carer>?</p>	Nodes\\AUTONOMY\\Regularity of carer

	<p>P9: Some of them are alright the majority of nights they're terrible</p> <p>Interviewer: What not talking?</p> <p>P9: No</p>	
P9 NARRATIVE	<p>They don't ask you how you are, how you're feeling.</p> <p>P9: No</p> <p>Interviewer: They just come in and then go</p> <p>P9: Yeah</p> <p>Interviewer: Is that what it's like?</p> <p>P9: Yeah</p> <p>Interviewer: How do you feel about that?</p> <p>P9: They're invading my privacy</p> <p>Interviewer: That's interesting, is that how it makes you feel?</p> <p>P9: Yes, they're spoiling it my spaceYeah</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Interviewer: Well I guess we all do that, some things we don't want to tell other people</p> <p>P9: It's not that I don't want to tell her it's that I don't know how to tell her</p> <p>Interviewer: Do you feel a need to tell her? Would you like to tell her?</p> <p>P9: Yeah</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Interviewer: What things does she do that makes her an angel?</p> <p>P9: She just talks to you like you're a person</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>Interviewer: You have friendly banter between you</p> <p>P9's husband: That's the word</p> <p>Interviewer: Ah that's nice isn't it, so you can actually engage in humour with her and laugh and have a joke</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 NARRATIVE	<p>And how does it make you feel when they come late?</p> <p>P9: Mad</p> <p>Interviewer: In what way?</p> <p>P9: It annoys me so much, I don't see how people can be late, there's no reason to be late is there?</p> <p>Interviewer: So it kind of messes you up does it?</p> <p>P9: Yeah</p>	Nodes\\AUTONOMY\\timing
P9 NARRATIVE	<p>They're supposed to come 8 o'clock in the morning, some don't come until half past 8, they're supposed to come 12 o'clock midday, sometimes they come at 20 past 12 and they're supposed to come at 7 o'clock at night and mostly they do come then</p>	Nodes\\AUTONOMY\\timing
P9 NARRATIVE	<p>P9's husband: Okay, no that's fantastic no so</p> <p><carer> is the one <P9> has struck up a great friendship with and she's close to her, I mean we</p>	Nodes\\ENGAGEMENT WITH OTHERS\\carer

	<p>don't have a completion over these things</p> <p>Interviewer: No, but she is someone else very important in <P9's> world, and she does personal care for her?</p>	
P9 NARRATIVE	<p>Does <p9> have any friends, or see any friends or go out?</p> <p>P9's husband: No, not particularly, we've got some neighbours that pop round to see her she gets along with.</p>	Nodes\\ENGAGEMENT WITH OTHERS\Friends
P9 NARRATIVE	<p>Interviewer: Does <P9> not want to get out and about?</p> <p>P9's husband: Not a lot, she feels vulnerable and now she physically can't, but no she didn't want to, she wanted to stay in which is why it's been so hard, having been a party animal and I very much am still</p>	Nodes\\ENGAGEMENT WITH OTHERS\Isolation
P9 NARRATIVE	<p>Interviewer: So for the last 10 years it's been just yourself and <P9>?</p> <p>P9's husband: Yes</p> <p>Interviewer: Does anybody else come in to the home at all?</p> <p>P9's husband: No, apart from my son who lives sort of 10 miles up the road</p>	Nodes\\ENGAGEMENT WITH OTHERS\Isolation
P9 NARRATIVE	<p>Interviewer: So you speak to <daughter> every day on the phone?</p> <p>P9: Yeah Oh I do wish she lived local?</p>	Nodes\\ENGAGEMENT WITH OTHERS\Isolation
P9 NARRATIVE	<p>Interviewer: You feel like saying, if you could order the world not to look at you and make you feel okay</p> <p>P9: That's it</p> <p>Interviewer: Do you miss going out?</p> <p>P9: Oh yes</p> <p>Interviewer: DO you? Especially weather like this I guess?</p> <p>P9: Yeah but I'd have to carry my oxygen around</p>	Nodes\\ENGAGEMENT WITH OTHERS\Isolation
P9 NARRATIVE	<p>Interviewer: Do they smile?</p> <p>P9: Sometimes, not all the time</p> <p>Interviewer: Okay, because the <P9> that <husband> was describing earlier was very laughy, chatty, smiley</p> <p>P9: Yes she is still there a bit</p> <p>Interviewer: And to have someone come into your home and not even introduce themselves must be hard for you</p> <p>P9: Oh yes it is</p>	Nodes\\SELF\earlier life experiences-self now
P9 NARRATIVE	<p>Interviewer: I was just saying what was <P9>'s social world now and how that is so different from her social world before she became ill?</p> <p>P9's husband: Before we got together as far as I know her and <ex-husband> used to go out but I don't know to what extent, while we were together we were out more than in, we were party animals</p>	Nodes\\SELF\ earlier life experiences-self now

P9 NARRATIVE	P9's husband: She was a manager of a single shop, of a bookmakers in the town centre Interviewer: And how old was P9 then? P9's husband: Mid thirties	Nodes\\SELF\\ earlier life experiences-self now
P9 NARRATIVE	Do you think she can identify with the <P9> that was a little bit? Does she bring out the old <P9>? P9: Not really, she hasn't reached that point yet	Nodes\\SELF\\ earlier life experiences-self now
P9 NARRATIVE	It's horrible, having to be stuck in all the time, I don't mind being stuck in now, I like it because I have to really push to go out now Interviewer: Do you prefer to be at home? P9: Yes well people stare at me Interviewer: Do they? And that worries you?	Nodes\\SELF\\getting older
P9 NARRATIVE	Interviewer: I can understand that P9: I feel embarrassed, I just don't want them to do it you know Interviewer: I'm sure <P9> so you actually tell them not to do you? P9: Yeah Interviewer: And you're alright telling them not to? P9: I just say 'I don't want a shower today'	Nodes\\SELF\\getting older\\Dignity
P9 NARRATIVE	Interviewer: But I guess what you're saying is when it's someone you don't know you find it difficult? P9: Yeah, because I won't let them shower me the strangers Interviewer: You don't like them to do that? P9: No	Nodes\\SELF\\getting older\\Dignity
P9 NARRATIVE	Interviewer: Does <P9> not want to get out and about? P9's husband: Not a lot, she feels vulnerable and now she physically can't, but no she didn't want to, she wanted to stay in which is why it's been so hard, having been a party animal and I very much am still	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	P9: It's horrible, having to be stuck in all the time, I don't mind being stuck in now, I like it because I have to really push to go out now Interviewer: Do you prefer to be at home? P9: Yes well people stare at me Interviewer: Do they? And that worries you?	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	Interviewer: SO, I mean coming back to my study, it's looking at home carers coming in has a sense on <P9> where she is right now, how comfortable she is with herself and I'm getting the picture that because you have <carer> who comes in and is a regular carer and very positive carer, and regular carers in the evening, then in effect they have a good relationship with <P9> P9's husband: Certainly encourages feelings of wellbeing I wouldn't say independence because <P9> doesn't have to be independent	Nodes\\SELF\\getting older\\Vulnerability

P9 NARRATIVE	<p>P9: No she's not gentle</p> <p>P9's husband: What do you mean? She doesn't knock you about</p> <p>P9: No she doesn't but she's not gentle I wouldn't like her to be gentle</p> <p>Interviewer: That's interesting, why's that?</p> <p>P9: Because I know I have to be dried and washed</p>	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	<p>Interviewer: So I was asking, how much time during the day <p9> is able to engage with yourself and with other people and how much she goes out and engages with the community.</p> <p>P9's husband: She just doesn't. Up until I had my cancer in 2010, she wouldn't let anybody else near her</p> <p>Interviewer: Okay, but would she actually communicate?</p> <p>P9's husband: She was up to a point, she wouldn't communicate with other people without me being there, and she wanted to me talk for her</p>	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	<p>Interviewer: So where does <p9> sleep?</p> <p>P9's husband: She sleeps there, that's where she spends 24 hours. She does not want to sleep in a bed. Because she's got a breathing tube one end and a catheter as you can see.</p>	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	<p>P9's husband: No no, she can walk on sticks with underarm support, at the moment if she's bad enough she can't do it, I don't leave her so I can help with a wheelchair as well. But generally speaking she has been able to walk. Yesterday we went to stand her up, and it's the second time it's happened over the last couple of days when her knees just completely went. She's obviously losing a great deal of her strength but I mean there's nothing we can do about that. It's like anybody going through a transition. Its better some days than others but if you look at it the beginning to the end you can see a decline</p>	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	<p>Interviewer: So how long has <p9> been in the situation where she's been asleep 16 hours a day?</p> <p>P9's husband: Since the last 10/20 years. Since she had the emphysema. She's on oxygen all time.</p>	Nodes\\SELF\\getting older\\Vulnerability
P9 NARRATIVE	<p>Interviewer: How do you feel about that? Coming into your home and being like that</p> <p>P9: They're invading my privacy</p> <p>Interviewer: That's interesting, is that how it makes you feel?</p> <p>P9: Yes, they're spoiling my space?</p>	Nodes\\SELF\\Home
P9 NARRATIVE	<p>P9: I don't mind some of them, some of them I don't like, because they come in on my privacy and I don't like that</p>	Nodes\\SELF\\Home

P9 NARRATIVE So do you say anything to them?
P9: No
Interviewer: Do they say anything to you about it?
P9: No
Interviewer: So it becomes the elephant in the
room no one wants to talk about?
P9: That's right
Interviewer: Does it cause tension?
P9: Yeah it does because I don't talk to them and
they don't talk to me

Nodes\\VOICING CONCERNS\don't make a fuss

P9 NARRATIVE Interviewer: I can understand that
P9: I feel embarrassed, I just don't want them to
do it you know
Interviewer: I'm sure <P9> so you actually tell
them not to do you?
P9: Yeah
Interviewer: And you're alright telling them not
to?
P9: I just say 'I don't want a shower today'

Nodes\\VOICING CONCERNS\ speak out

APPENDIX 5B

Thematic analysis for Susan's Diary

Thematic Analysis for Susan's Diary

P9 DIARY	washed them up. She and <regular carer> always do that and <another carer> but the others don't.	Nodes\\AUTONOMY\model of care\going beyond the task list
P9 DIARY	<Carer> is a fabulous cook and tonight she brought us some cakes. Wow! They were fabulous! I said to her that I could get used to this kind of treatment and she has promised to do some more before <regular carer> comes back. Again she chatted and stayed her full time. She has all the time in the world for us and never rushes to leave. If my whole caring was done by her and <regular carer> I would be the luckiest person in the world but sadly I know this won't happen.	Nodes\\AUTONOMY\model of care\going beyond the task list
P9 DIARY	I had to show her where everything was and at lunchtime my husband had to tell her to do my dinner and she was ready to go without doing anything, when she did speak though she was quite pleasant.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	Today at breakfast I had a carer who only comes occasionally. She is pleasant and chatty, but doesn't wash me as thoroughly as others so I don't feel as clean.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	I had <another carer> at lunchtime and she is steady and reliable. She made my lunch and sat and had a chat for a while The carer who came tonight is <name> she is the one with long nails and even though I told her I was in pain she rubbed me very hard and I had to tell her to stop. When she came in she asked how I was but before I could say anything she started talking about herself. What a difference between her and the others, they are proper carers – she is not	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	It was supposed to be <regular carer's> day off but she was asked to cover the morning. It is good for me because I know I will always be washed, dried and creamed properly, and then my breakfast exactly as I like it. At lunchtime I had one of the regular reliefs who is starting to treat me better. It is not that she has not been good in the past, but always kept a certain distance between us. Over the last few weeks it has been clear she is starting to have more conversations and taking her time after filling in the book to spend a few minutes chatting to me. This makes the visits much nicer. The lady who came tonight is also a regular. She is always competent at her job but while she is always polite is not necessarily always friendly and chatty. When there are inconsistencies like this, it always leaves me on edge as I don't know what to expect. At least with <regular carer> my care and considerations are always consistent. This makes me feel special.	Nodes\\AUTONOMY\Regularity of carer

P9 DIARY	Over the two weeks <Regular carer> is away she is going to be coming and I can now relax knowing I will be cared for as well as I am by <regular carer>. After getting my breakfast she sat and chatted to me for a while. Even though my pain is high I have felt happy in a relieved way, as I know I will be cared for properly.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	But <regular carer> sets a very high standard and is hard to equal.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	My regular carer was away today and this morning and lunch time I had a new young carer. Not having met her before I felt uncertain. She did not introduce herself on either occasion and because of my wariness of her I did not let her shower me.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	That is no problem as everyone has to learn, but I find they always make my coffee very strong in spite of the fact I tell them I like it weak.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	<Regular carer> here again today, what can I write that hasn't been written or said many times before. Everything at breakfast and lunch was spot on. <Regular carer> is only here the same time as everyone else but gets everything done, always perfect (though I don't tell her so) and she always has time for a good chat. She even washes up	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	Had one of the younger carers today at breakfast. She seems quite nice and chatty but I feel rather self-conscious and asked for her only to give me a towel wash. MY husband was walking the dog so I had to tell her where to find things.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	<Regular carer> was back today, all 3 times. What can I say that isn't overstated? She straight away empties my overnight catheter, gets me up and walks me slowly to shower room. Gets me ready then showers me properly everywhere. When drying me she towels me down gently but thoroughly. All the creams I need are properly but gently rubbed in and she is so sensitive but firms in her manner. When finished I feel properly clean and cared for. She makes me feel important – special and it is like heaven. On each visit, she gets my meals (except evening), cares for me properly, talks to me, and although she had a fixed time limit she seems to do things at my pace and treats me like an individual.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	We had someone tonight who is affectionately known as <nick name> because she has a high pitched voice. We had a good chat, I asked her about her home life and she told me she is a carer for her brother but works when she can. I was left full of admiration for her	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	She also left all the tops off the cream and left in a hurry. When she first started some months ago I thought she was quite nice but over time has done on she has become less caring in her nature and always talking about her own problems and doesn't often ask about me or how I am. She when talks to me she called me <shortening of name> and I don't like that.	Nodes\\AUTONOMY\\Regularity of carer

	Tomorrow my regular carer will be back and I will feel better as she makes me feel important and looks after me properly.	
P9 DIARY	I had a lovely surprise today. <Regular carer> has gone on holiday for 2 weeks and I wasn't looking forward to anyone else. But when <husband> opened the door it was <old regular carer> who like <regular carer> makes me feel special, that I am the only person she sees and we have a good laugh.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	Tonight I had a regular helper who didn't wait for me to finish my dinner so she could cream my legs. I tried to eat while this was going on.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	I had <unliked carer> back again with her long nails. She hasn't cut me with them this time but caught me and I told her, she said sorry but carried on regardless.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	When she had finished writing in the book she shut it, put it away and said 'I always like coming to you as I can always shoot off quick to make up for lost time!	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	<Different carer> came in at lunch time, she is very friendly and quite good. She chats to me when tending to me and does ok but it not quite as thorough. At least she is nice too.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	when she is washing, or drying, or putting my creams on she is very careful but thorough.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	<Carer> is a fabulous cook and tonight she brought us some cakes. Wow! They were fabulous! I said to her that I could get used to this kind of treatment and she has promised to do some more before <regular carer> comes back. Again she chatted and stayed her full time. She has all the time in the world for us and never rushes to leave. If my whole caring was done by her and <regular carer> I would be the luckiest person in the world but sadly I know this won't happen.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	We had a good laugh and chat while she was washing me and while eating my breakfast she stayed and chatted	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	<Carer> is a fabulous cook and tonight she brought us some cakes. Wow! They were fabulous! I said to her that I could get used to this kind of treatment and she has promised to do some more before <regular carer> comes back. Again she chatted and stayed her full time. She has all the time in the world for us and never rushes to leave. If my whole caring was done by her and <regular carer> I would be the luckiest person in the world but sadly I know this won't happen.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	Then she told <husband> to go out with dog again for 20 minutes and while they were gone she sat and chatted with me	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	Also, she never brings any of her problems with her. All the time she talks to me about me, she asks how I am feeling and where I am in pain,	Nodes\\AUTONOMY\Regularity of carer

P9 DIARY	All she did was moan either about her problems or some of her clients, which tells me she must do the same thing with me	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	<Different carer> came in at lunch time, she is very friendly and quite good. She chats to me when tending to me and does ok but it not quite as thorough. At least she is nice too.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	She also left all the tops off the cream and left in a hurry. When she first started some months ago I thought she was quite nice but over time has done on she has become less caring in her nature and always talking about her own problems and doesn't often ask about me or how I am. She when talks to me she called me <shortening of name> and I don't like that.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	My regular carer was away today and this morning and lunch time I had a new young carer. Not having met her before I felt uncertain. She did not introduce herself on either occasion and because of my wariness of her I did not let her shower me.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	When he had gone she talked to me in a more calm and nice manner. She said to me to tell her if anything was not as I wanted. She kept apologising and I said to put it behind her and she said 'thank you for understanding'.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	It was supposed to be <regular carer's> day off but she was asked to cover the morning. It is good for me because I know I will always be washed, dried and creamed properly, and then my breakfast exactly as I like it. At lunchtime I had one of the regular reliefs who is starting to treat me better. It is not that she has not been good in the past, but always kept a certain distance between us. Over the last few weeks it has been clear she is starting to have more conversations and taking her time after filling in the book to spend a few minutes chatting to me. This makes the visits much nicer. The lady who came tonight is also a regular. She is always competent at her job but while she is always polite is not necessarily always friendly and chatty. When there are inconsistencies like this, it always leaves me on edge as I don't know what to expect. At least with <regular carer> my care and considerations are always consistent. This makes me feel special.	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	I talked with <carer who's replacing regular carer> about it and she was very good listening to me and understanding my situation. She is very gentle with me and even though I feel awful I still have a sense of feeling better after she has been	Nodes\\AUTONOMY\Regularity of carer
P9 DIARY	I had a lovely surprise today. <Regular carer> has gone on holiday for 2 weeks and I wasn't looking forward to anyone else. But when <husband> opened the door it was <old regular carer> who like <regular carer> makes me feel special, that I am the only person she sees and we have a good laugh.	Nodes\\AUTONOMY\Regularity of carer

P9 DIARY	On each visit, she gets my meals (except evening), cares for me properly, talks to me, and although she had a fixed time limit she seems to do things at my pace and treats me like an individual.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	when she is washing, or drying, or putting my creams on she is very careful but thorough. Over the two weeks <Regular carer> is away she is going to be coming and I can now relax knowing I will be cared for as well as I am by <regular carer>. After getting my breakfast she sat and chatted to me for a while. Even though my pain is high I have felt happy in a relieved way, as I know I will be cared for properly.	Nodes\\AUTONOMY\\Regularity of carer
P9 DIARY	<Regular carer> was back today and so I had a good wash and shower. Breakfast was perfect. She didn't come out again until 1.00PM and said the office had moved out time to accommodate another customer. My husband was really angry they had done this especially without consulting us.	Nodes\\AUTONOMY\\timing
P9 DIARY	He got on the phone, demanded to speak to the boss and promptly gave her a piece of his mind. I was quite surprised how calm and direct he was, and left her in no doubt he would cancel the contract if they put me second again. She apologised asked to speak with <regular carer> and told her to go back to the correct time tomorrow.	Nodes\\AUTONOMY\\timing
P9 DIARY	My lunch time caller didn't get here until 1.00PM. My husband was furious as my medication and food at this part of the day is time dependant, and he said it would be ok now and then if they called and let us know.	Nodes\\AUTONOMY\\timing
P9 DIARY	When she had finished writing in the book she shut it, put it away and said 'I always like coming to you as I can always shoot off quick to make up for lost time!	Nodes\\AUTONOMY\\timing
P9 DIARY	On each visit, she gets my meals (except evening), cares for me properly, talks to me, and although she had a fixed time limit she seems to do things at my pace and treats me like an individual.	Nodes\\SELF\\earlier life experiences-self now
P9 DIARY	Tomorrow my regular carer will be back and I will feel better as she makes me feel important and looks after me properly.	Nodes\\SELF\\ earlier life experiences-self now
P9 DIARY	I talked with <carer who's replacing regular carer> about it and she was very good listening to me and understanding my situation. She is very gentle with me and even though I feel awful I still have a sense of feeling better after she has been	Nodes\\SELF\\ earlier life experiences-self now
P9 DIARY	I had a lovely surprise today. <Regular carer> has gone on holiday for 2 weeks and I wasn't looking forward to anyone else. But when <husband> opened the door it was <old regular carer> who like <regular carer> makes me feel special, that I am the only person she sees and we have a good laugh.	Nodes\\SELF\\ earlier life experiences-self now

P9 DIARY	Had one of the younger carers today at breakfast. She seems quite nice and chatty but I feel rather self-conscious and asked for her only to give me a towel wash.	Nodes\\SELF\\ earlier life experiences-self now
P9 DIARY	My lunch time caller didn't get here until 1.00PM. My husband was furious as my medication and food at this part of the day is time dependant, and he said it would be ok now and then if they called and let us know.	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	Tonight I had a regular helper who didn't wait for me to finish my dinner so she could cream my legs. I tried to eat while this was going on.	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	uncertain. She did not introduce herself on either occasion and because of my wariness of her I did not let her shower me. I don't like this being done by strangers and so I just had a little wash.	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	When she had finished writing in the book she shut it, put it away and said 'I always like coming to you as I can always shoot off quick to make up for lost time!	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	She left me in the bathroom while she wrote in the book.	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	She has very long ginger nails and scratched me while applying the cream.	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	She used the towel that is used to dry me to mop it up and then put the towel back on the rail for me	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	I had <unliked carer> back again with her long nails. She hasn't cut me with them this time but caught me and I told her, she said sorry but carried	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY	The GP phoned back and had a chat, he was concerned about the amount I need and wants me to go back to hospital to see about having the operation. I get the feeling he is more concerned	Nodes\\SELF\\getting older\\Vulnerability
P9 DIARY P9 DIARY	The GP phoned back and had a chat, he was concerned about the amount I need and wants me to go back to hospital to see about having the operation. I get the feeling he is more concerned about the cost of my medicine rather than my long term welfare. I hope I'm wrong, but it's scary! When <regular carer> is back tomorrow I will be	Nodes\\SELF\\getting older\\Vulnerability Nodes\\VOICING CONCERNS\\don't make a fuss
P9 DIARY	<Husband> helped me back, I think he was about to say something but I squeezed his arm and shook my head as best I could, as I know he would have been quite scathing.	Nodes\\VOICING CONCERNS\\don't make a fuss
P9 DIARY	I said I probably wouldn't tell her as I don't have the confidence to so, but that my husband would.	Nodes\\VOICING CONCERNS\\don't make a fuss
P9 DIARY	She is pleasant and chatty, but doesn't wash me as thoroughly as others so I don't feel as clean. When I told my husband he said she would have a	Nodes\\VOICING CONCERNS\\don't make a fuss
P9 DIARY	<Husband> helped me back, I think he was about to say something but I squeezed his arm and shook my head as best I could, as I know he would have been quite scathing.	Nodes\\VOICING CONCERNS\\don't make a fuss

P9 DIARY	She is pleasant and chatty, but doesn't wash me as thoroughly as others so I don't feel as clean. When I told my husband he said she would have a worked but I said no as I do not want any more	Nodes\\VOICING CONCERNS\don't make a fuss
P9 DIARY	It is Sunday and they have sent the lady with whom we had the issues. What a difference! In the morning I was washed dried and creamed absolutely perfectly. She took her time and did everything is a textbook manner. At lunch I was	Nodes\\VOICING CONCERNS\Speak out\
P9 DIARY P9 DIARY	It is Sunday and they have sent the lady with whom we had the issues. What a difference! In the morning I was washed dried and creamed absolutely perfectly. She took her time and did everything is a textbook manner. At lunch I was again creamed and then fed as if I were the queen. I think they have realised I will not be treated	Nodes\\VOICING CONCERNS\Speak out\ Nodes\\VOICING CONCERNS\Speak out
P9 DIARY	He got on the phone, demanded to speak to the boss and promptly gave her a piece of his mind. I	Nodes\\VOICING CONCERNS\Speak out
P9 DIARY P9 DIARY	He got on the phone, demanded to speak to the boss and promptly gave her a piece of his mind. I was quite surprised how calm and direct he was, and left her in no doubt he would cancel the contract if they put me second again. She apologised asked to speak with <regular carer> and told her to go back to the correct time tomorrow.	Nodes\\VOICING CONCERNS\Speak out Nodes\\VOICING CONCERNS\Speak out
P9 DIARY	The other day my husband mentioned to a supervisor about the carer who scratched me. He also told them he wasn't satisfied she was up for the job of caring for me. This resulted in the owner speaking to him and saying if he were to address these issues with the carer it would give	Nodes\\VOICING CONCERNS\Speak out
P9 DIARY P9 DIARY	The other day my husband mentioned to a supervisor about the carer who scratched me. He also told them he wasn't satisfied she was up for the job of caring for me. This resulted in the owner speaking to him and saying if he were to address these issues with the carer it would give her a second chance as they are short staffed and couldn't afford to lose more staff. Tonight she was sent to see us apologised and my husband made it abundantly clear if she did not treat me in a dignified professional manner and to a high acceptable standard consistently then there would be no further chances. Just before she went she said she had learned a few valuable lessons today, one of which was to	Nodes\\VOICING CONCERNS\Speak out Nodes\\VOICING CONCERNS\Speak out
P9 DIARY	She wanted to make sure that I was ok with the outcome of the chat we had had with the carer from the recent problems. We had some good chats and she told me she would come at least once a week from now on to make sure if I had	Nodes\\VOICING CONCERNS\Speak out

APPENDIX 5C

Thematic analysis for Susan's Follow-up Interview

Thematic Analysis for Susan's Follow-up Interview

P9 FOLLOW UP IV	<p>Interviewer: So do you manage the budget yourself then?</p> <p>P9's husband: We're self-funded, with self-direct support. So they give us the money and we spend it</p>	Nodes\\AUTONOMY\Funding
P9 FOLLOW UP IV	<p>P9's husband: I understand exactly what you're saying, and that's it, and it's a pity I didn't actually put it in that book as such but you've captured it spot on there, when she's had a visit from somebody who's made her feel good, she feels a lot better for a long time afterwards, almost always, obviously not when she's got days with chronic number 10 pain then it doesn't, but we're talking about the times when <P9>'s got the ability, not pain free, but better pain controlled when the niceties have a beneficial effect on her, and if it has a beneficial effect on her it has a beneficial effect on me so it's a win win situation</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>P9's husband: Well, if somebody makes you feel, has a go at you and you're not the sort of person who gets back at them and you feel down and sort of heavy and burdened but when somebody pays you compliments, treats you special, you bounce around on your toes, I know <P9> can't bounce around on her toes physically but she still can mentally</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>Interviewer: How did you feel being left sat on the toilet with the lid down?</p> <p>P9: Seething</p> <p>Interviewer: Why was that?</p> <p>P9: Because she just dumped me there and as if she just dumped me there, left me there, and said right you get on with it now</p> <p>Interviewer: Again, not treating you like an individual with the restrictions you have in terms of your mobility. So was it not respecting you as a person?</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>P9: No, just not be on this earth</p> <p>P9's husband: Well yeah that is worthless <P9></p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>P9: I always feel guilty, it's always my thought, and it's a privilege for me to be on earth, you know, they make me feel I shouldn't be here</p> <p>Interviewer: What, some of the carers?</p> <p>P9: Yeah</p> <p>Interviewer: Do they make you feel that bad?</p> <p>P9: Yeah</p>	Nodes\\AUTONOMY\Regularity of carer

P9 FOLLOW UP IV	<p>P9: Because I don't know who I'm talking to. It could be a man or woman off the street.</p> <p>Interviewer: So it makes you feel almost a bit threatened or nervous</p> <p>P9: It makes me feel like a baby again</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>someone new coming into your home</p> <p>P9: I wish they would tell me who they are</p> <p>Interviewer: And so when someone comes in that you've never met before and he or she doesn't introduce themselves, how does that make you feel as a person?</p> <p>P9: Makes me annoyed and angry</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>P9's husband: And turning the clock back up until about a year ago, <previous carer> used to have every other weekend off and in that time we used to have a young girl who was in college, university, used to do it at weekends, anyway she was only sort of late teens/early twenties and <p9> wouldn't let her do it. And she would go from the time <carer> did it on Friday morning to Monday morning, bearing in mind that <p9> occasionally has continence issues and that, I have to change her nightie a couple of times a day because she mucks herself, it can't be helped and I obviously help to get her cleaned but it's not the same as a shower.</p> <p>Interviewer: So there are these consequences of feeling uncomfortable with a carer, health consequences</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>P9: That's right, yes she does, and she leaves me on a high.</p> <p>Interviewer: Isn't that brilliant. Do you think that affects you not only emotionally that you feel so much better but do you think it has an effect on you psychically as well?</p> <p>P9: Yeah</p> <p>P9's husband: Well yes I can see that, because</p> <p>Interviewer: It must affect your breathing or</p> <p>P9: Yeah</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>P9's husband: What she said to me was, was 'They never go out of the door and leave me without a smile on my face'</p> <p>Interviewer: Well how important is that!</p> <p>P9's husband: And looking forward to when they come again, and disappointed when they don't</p>	Nodes\\AUTONOMY\Regularity of carer
P9 FOLLOW UP IV	<p>Interviewer: Because another carer came in and just unloaded all of their problems onto you</p> <p>P9's husband: Yeah that's right, so when they go, <P9> feels as if she's got the problems of the world on her shoulders And she feels heavie</p> <p>Well she can't cope with it</p>	Nodes\\AUTONOMY\Regularity of carer

P9 FOLLOW UP IV	<p>P9: Well people come in and look over my head that's why I'm desperate to do my neck. They look over my head and talk to <husband>. They don't bother with me, I'm not there. „makes me feel unimportant</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 FOLLOW UP IV	<p>Interviewer: So she called you that instead of your actual name? You hadn't given her permission as you don't like to be called that P9: No I don't Interviewer: So you hadn't given her permission to call you something different. How did it make you feel? P9: I just didn't like it. My name is <P9>. I just don't like that word. Interviewer: Did you challenge her on it? P9: No</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 FOLLOW UP IV	<p>Interviewer: Before you became ill <p9> you were very competent, very confident and outgoing and a great communicator from what I heard in the first interview P9's husband: She was Interviewer: But now you're in a situation where someone new comes into your home and they don't even have eye contact with you. P9: That's right P9's husband: Yeah, well it means <p9> is a job. Well that's it, it is. Interviewer: Does it make you feel like that? P9: Yeah it does Interviewer: Just a number on a sheet? Not a person? P9: That's right P9's husband: Not an individual</p>	Nodes\\AUTONOMY\\Regularity of carer
P9 FOLLOW UP IV	<p>P9's husband: Well the whole point is, and this is nationwide, the carers are given a certain slot, what we've learned round here and I would imagine it's widespread, they know which ones they can shoot through. The lady I just told you about down the road, pays for it privately, she pays for either ¾ of an hour or an hour and she expects them to stay that long. <p9> because we're funded has a 45 minute slot in the morning, a 30 minute slot in the afternoon and a 30 minute slot in the evening, but if I'm here as I'm more often than not out, especially in the evening preparing dinner and they're running a bit late or they want to make up some time to get off early, they'll come in, cream <p9> in and out 7 minutes, do the books and I can promise you they'll be out of that door inside of half the time they're supposed to be here. I should say something, but if I did, I would end up complaining 30, 40 % of the time and I don't want it.</p>	Nodes\\AUTONOMY\\timing
P9 FOLLOW UP IV	<p>Interviewer: Have you always had a good sense of humour? P9: I used to, used to Interviewer: So you still like someone who comes in here and can still make you laugh</p>	Nodes\\SELF\\earlier life experiences-self now

	<p>P9's husband: She was a good practical joker up to a point, but <P9> was one of these who could look you straight in the eye and tell you a story and you wouldn't know, she could really wind you up</p>	
P9 FOLLOW UP IV	<p>P9's husband: Now, I can't think which one that might have been. I've got a rough idea, again its back to the situation where <P9> doesn't like young people seeing her naked Interviewer: Why would that be? P9's husband: She just gets very self-conscious. Can I just ask you the question for a minute <P9>? What is it when you get young carers, and you don't want them to wash you, you don't like them to see your body do you? Can you say why that is, do you know why? P9: Because I've put on so much weight. I know it's not my fault it's the tablets fault why I put on weight but I feel self-conscious because of that and because I've got a catheter. I just don't want young people touching me Interviewer: Before you became ill <p9> you were very competent, very confident and outgoing and a great communicator from what I heard in the first interview P9's husband: She was Interviewer: But now you're in a situation where someone new comes into your home and they don't even have eye contact with you. I mean, that tells me, where's <p9> in that process? P9: That's right P9's husband: Yeah, well it means <p9> is a job. Interviewer: Ah, is that how you feel? A number on a sheet? P9's husband: Well that's it, it is. Interviewer: Does it make you feel like that? P9: Yeah it does Interviewer: Just a number on a sheet? Not a person? P9: That's right P9's husband: Not an individual</p>	Nodes\\SELF\ earlier life experiences-self now
P9 FOLLOW UP IV	<p>Interviewer: So this is a new characteristic? P9's husband: Well she was perfectly capable of standing up for herself when I first met her. Interviewer: Before you became ill <p9> you were</p>	Nodes\\SELF\ earlier life experiences-self now

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P9 FOLLOW UP IV	<p>P9: Well people come in and look over my head that's why I'm desperate to do my neck. They look over my head and talk to <husband>. They don't bother with me, I'm not there.</p>	Nodes\\SELF\ earlier life experiences-self now

P9 FOLLOW UP IV	<p>P9: Because I don't know who I'm talking to. It could be a man or woman off the street.</p> <p>Interviewer: So it makes you feel almost a bit threatened or nervous</p> <p>P9: It makes me feel like a baby again</p>	Nodes\\SELF\ earlier life experiences-self now
P9 FOLLOW UP IV	<p>P9's husband: Well the thing is, before they provide this service, they assess us, they have to know that, they have been told that <p9> was attacked at gun point which you know, had a nervous breakdown, this bubbly person went forever and I've now got this closeted lady who's frightened of other people and on the defensive because she's a little bit unsure of herself and of them</p>	Nodes\\SELF\ earlier life experiences-self now
P9 FOLLOW UP IV	<p>P9's husband: Now, I can't think which one that might have been. I've got a rough idea, again its back to the situation where <P9> doesn't like young people seeing her naked</p> <p>Interviewer: Why would that be?</p> <p>P9's husband: She just gets very self-conscious. Can I just ask you the question for a minute <P9>? What is it when you get young carers, and you don't want them to wash you, you don't like them to see your body do you? Can you say why that is, do you know why?</p> <p>P9: Because I've put on so much weight. I know it's not my fault it's the tablets fault why I put on weight but I feel self-conscious because of that and because I've got a catheter. I just don't want young people touching me</p>	Nodes\\SELF\ earlier life experiences-self now
P9 FOLLOW UP IV	<p>Interviewer: So this is a new characteristic?</p> <p>P9's husband: Well she was perfectly capable of standing up for herself when I first met her.</p> <p>P9's husband: Now, I can't think which one that might have been. I've got a rough idea, again its back to the situation where <P9> doesn't like young people seeing her naked</p> <p>Interviewer: Why would that be?</p> <p>P9's husband: She just gets very self-conscious. Can I just ask you the question for a minute <P9>? What is it when you get young carers, and you don't want them to wash you, you don't like them to see your body do you? Can you say why that is, do you know why?</p> <p>P9: Because I've put on so much weight. I know it's not my fault it's the tablets fault why I put on weight but I feel self-conscious because of that and because I've got a catheter. I just don't want young people touching me</p>	Nodes\\SELF\getting older\Vulnerability

P9 FOLLOW UP IV

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P9's husband: And turning the clock back up until about a year ago, <previous carer> used to have every other weekend off and in that time we used to have a young girl who was in college, university, used to do it at weekends, anyway she was only sort of late teens/early twenties and <p9> wouldn't let her do it. And she would go from the time <carer> did it on Friday morning to Monday morning, bearing in mind that <p9> occasionally has continence issues and that, I have to change her nightie a couple of times a day because she mucks herself, it can't be helped and I obviously help to get her cleaned but it's not the same as a shower.
Interviewer: So there are these consequences of feeling uncomfortable with a carer, health consequences

Nodes\\SELF\\getting older\\Vulnerability

P9 FOLLOW UP IV

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P9's husband: It doesn't bother me up to a point but I know that it bothers <P9>, she gets terribly embarrassed when she's unclean. Can we change this bit of the conversation because I think that <p9> is getting a bit upset?

Interviewer: Are you upset <p9>?

P9: Yes a bit

P9 FOLLOW UP IV

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Interviewer: Are you upset <p9>?

P9: Yes a bit

Nodes\\SELF\\getting older\\Vulnerability

P9 FOLLOW UP IV	<p>P9: I always feel guilty, it's always my thought, and it's a privilege for me to be on earth, you know, they make me feel I shouldn't be here</p> <p>Interviewer: What, some of the carers?</p> <p>P9: Yeah</p> <p>Interviewer: Do they make you feel that bad?</p> <p>P9: Yeah</p> <p>Interviewer: Worthless you mean?</p> <p>P9: No, just not be on this earth</p> <p>P9's husband: Well yeah that is worthless <P9></p> <p>Interviewer: A burden, perhaps?</p> <p>P9: Maybe</p> <p>Interviewer: So she uses you to make up for the time she has spent with other people? How does that make you feel?</p> <p>P9: Degraded</p> <p>Interviewer: I think you've got a great vocabulary</p> <p><P9> I think degraded has probably hit the nail on the head hasn't it?</p> <p>P9's husband: That's right</p>	Nodes\\SELF\\getting older\\Vulnerability
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P9 FOLLOW UP IV	<p>P9: Well people come in and look over my head that's why I'm desperate to do my neck. They look over my head and talk to <husband>. They don't bother with me, I'm not there.</p> <p>Interviewer: So it makes you feel unimportant</p> <p>P9: Yeah</p> <p>P9: Because I don't know who I'm talking to. It could be a man or woman off the street.</p> <p>Interviewer: So it makes you feel almost a bit threatened or nervous</p> <p>P9: It makes me feel like a baby again</p> <p>P9's husband: Well, if somebody makes you feel, has a go at you and you're not the sort of person who gets back at them and you feel down and sort of heavy and burdened but when somebody pays you compliments, treats you special, you bounce around on your toes, I know <P9> can't bounce around on her toes physically but she still can mentally</p>	Nodes\\SELF\\getting older\\Vulnerability\\

P9 FOLLOW UP IV	<p>P9: Because I don't know who I'm talking to. It could be a man or woman off the street.</p> <p>Interviewer: So it makes you feel almost a bit threatened or nervous</p> <p>P9: It makes me feel like a baby again</p>	Nodes\\SELF\\getting older\\Vulnerability\\
P9 FOLLOW UP IV	<p>Interviewer: So did you feel vulnerable that you may fall off of the toilet?</p> <p>P9: I couldn't get up, I was just dumped there, I thought I might be there hours because sometimes <husband> his ears get blocked and he can't hear me</p> <p>P9: That's right, yes she does, and she leaves me on a high.</p> <p>Interviewer: Isn't that brilliant. Do you think that affects you not only emotionally that you feel so much better but do you think it has an effect on you psychically as well?</p> <p>P9: Yeah</p> <p>P9's husband: Well yes I can see that, because</p> <p>Interviewer: It must affect your breathing or</p> <p>P9: Yeah</p> <p>me</p>	Nodes\\SELF\\getting older\\Vulnerability\\
P9 FOLLOW UP IV	<p>Interviewer: Why's that? I mean I can understand why not but I wonder if you could explain.</p> <p>P9: I feel nervous in case they shout at me.</p> <p>Interviewer: Right, okay, is that in case your care is affected?</p> <p>P9: No</p> <p>Interviewer: You just, at that moment you'd be worried they might shout at you and then upset you?</p> <p>P9: Yes</p> <p>Interviewer: SO is it easier to let it go</p> <p>P9: Yes</p> <p>Interviewer: Okay, so is it being afraid of getting into an argument situation</p> <p>P9: No, I wouldn't argue</p> <p>Interviewer: Okay, so just being shouted at</p> <p>P9: I'd just cry</p> <p>Interviewer: You don't want to be shouted at</p> <p>P9's husband: She wouldn't argue back because she wouldn't have the confidence</p>	Nodes\\VOICING CONCERNS\\don't make a fuss
P9 FOLLOW UP IV	<p>Interviewer: Okay, so is it being afraid of getting into an argument situation</p> <p>P9: No, I wouldn't argue</p> <p>Interviewer: Okay, so just being shouted at</p> <p>P9: I'd just cry</p> <p>Interviewer: You don't want to be shouted at</p>	Nodes\\VOICING CONCERNS\\don't make a fuss

	<p>P9's husband: She wouldn't argue back because she wouldn't have the confidence</p> <p>Interviewer: So it's a balancing act is it?</p> <p>P9's husband: It is yes</p> <p>Interviewer: So you think it's between to keep quiet otherwise you might lose the good care that you get?</p> <p>P9's husband: Yeah</p> <p>Interviewer: Okay so that's about reporting and not reporting. Would you say it's about the energy needed as well to do the reporting?</p> <p>P9's husband: Well yes, that as well</p>	
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P9 FOLLOW UP IV

P9's husband : Well also because of the fact, I know with this agency, there is a strong chance if you do complain they will really defend the carer you're complaining against.

Interviewer: So it's a balancing act is it?

P9's husband: It is yes

Interviewer: So you think it's between to keep quiet otherwise you might lose the good care that you get?

P9's husband: Yeah

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P9's husband: Well yes, that as well

Nodes\\VOICING CONCERNS\don't make a fuss

APPENDIX 6

Vignettes

Vignettes

Maurice

Maurice is 74 and lives with his 70 year old wife. He has been disabled all of his adult life, being unable to walk unaided. Having perthes as a child left him disabled with osteoarthritis in many joints by the time he was 18. He has various other medical conditions (asthma, epilepsy). His wife, who is physically very able, was a hospital ward manger and takes great pride in keeping everything in order for Maurice. Whilst she manages the carers and his care extremely well, she is beginning to feel the strain as Maurice's health deteriorates and as she gets older.

Maurice takes great pride in their very strong family of two children and several grandchildren. Family pictures are all around and he tells lovely stories about their grandchildren and obviously very much enjoys the grandfather role. He receives support from family, but his wife very much keeps things in order at home. Maurice is always extremely smartly dressed and takes great pride in his personal grooming as does his wife. He says he has always been like this and even though he has been disabled he has always wanted to present a positive image to the world.

Maurice has carers 4 times a day to help him wash dress and go to the toilet. He sleeps in his adapted chair in the lounge so that he can walk himself using his frame to the toilet in the night but wears a pad in case he can't make it. He has the same carers and has done now for many years. They have become 'friends' and generally the care works very well. Occasionally (holidays, sickness etc.) he has new carers and he sometimes finds it a challenge when has to tell them where things are and what he likes etc..

My reflective notes include comments about how positive Maurice remains when he is obviously in pain and so limited in his mobility. Between my first and last visit he had a fall and was lying on the ground in the garden for an hour waiting for the ambulance. His left side was covered in bruises and he was in a great deal of discomfort, yet he was still smiling and positive and they were both laughing about it. When I explored this with Maurice, he attributed his positivity and forbearance to the fact that he has been disabled all of his adult life.

Susan

Susan aged 72 and lives with her husband. She has a spinal disc problem which means she is unable to walk unaided and also suffers from Chronic Obstructive Pulmonary Disease which means she uses an oxygen mask for most of the day. She is also on morphine which makes her very drowsy but it helps to manage the back pain. She also struggles to lift her head and much of the time she talks without making eye contact and her chin rests on her chest. Her husband, who was in attendance throughout my visits, thinks this is because she has been in the chair 24 hours a day for many years. She has carers visit 4 times a day to help her wash dress and go to the toilet. She has a catheter that is permanently fixed to her side which the carers empty when they visit. She rarely goes outside. She has 2 daughters who she rarely sees but she talks to one on the phone almost daily.

Her husband tells of how, in 1984 when they first met she was vivacious and bubbly, yet now she sleeps for much of the day and night and is reluctant to speak much at all. However, when she was able, Susan she was very keen to tell me about how awful some carers were, how they didn't introduce themselves, how they ignore her and how they sometimes hurt her with 'scratchy' nails. Yet she was very reluctant to complain to them directly, leaving that to her husband. Sometimes, however, she asked him not to complain because she was concerned about her care if they revisited. She has formed a very strong bond with one carer who has been visiting for several years and Susan is very happy when she attends. Susan's husband keeps very tight control over her care, making sure her food is prepared 'perfectly' and that everything on a personal level is done with utmost care and attention.

Susan does not like to go outside as she feels other people are staring at her with her oxygen tank and because she is unable to lift her head. Susan and her husband do try to get away to a holiday cottage where she can remain isolated, but she rarely interacts with others.

Clare

Clare aged 82 has multiple sclerosis and cannot walk unaided. She lives alone after her husband died almost 20 years ago. Carers visit three times a day to help her wash, dress and go to the toilet. Her niece attends early evening and sleeps in the spare room, checking that Clare is in bed until the early morning carer visit. Clare attends the day centre twice a week and engages well with other members. She is talkative and enjoys having company, wanting me to stay with her after the interview. She was really keen to complete the diary and I left it

with her in her walking frame next to her where she keeps her personal paperwork. When I returned to collect the diary she was disappointed because the carers had taken it away from her saying she did not need to write in a diary. They had placed it on the other side of the room where she could not reach it. She felt uncomfortable challenging them, hence the diary was not completed. She was, however, happy to do the follow-up interview and to talk about this. She recounts how the carers will often fall asleep in the chair next to her rather than helping her. They will also turn up late for visits meaning she cannot go to the day centre as she needs to be in her wheelchair ready for the bus driver. However, she makes excuses for the carers, not wanting to challenge them, and yet she also knows that their behaviour is wrong. She worries about getting on the wrong side of the carers.

Janet

Janet is an 82 year old woman who has multiple sclerosis and has had a stroke. She lives alone having been widowed many years ago. She can walk very limited distances with the aid of a frame or sticks. She tires easily and needs help with managing the home, shopping and cleaning but does not need help with her personal care. A carer visits twice a week and Janet relies very heavily on this support to maintain control over her environment and to present herself to the world. She is very well presented as is her home and she takes great pride in her appearance. She expresses anger and frustration that she is now older and cannot do what she used to. She has a good relationship with her carers who have been visiting for over a year. She attends various clubs and societies to keep herself engaged and challenged. She had nothing but glowing reports for her carers. Janet struggles with ageing and how others see her, as she feels much younger than she appears to others.

Karen

Karen is a 67 year old woman who lives alone. She was diagnosed with Parkinson's disease many years ago. She has limited mobility and cannot walk unaided. She has never been married and lived with her father until he died recently. Carers visit three times a day to help Karen in and out of bed and to help her get washed and dressed. They also help prepare food for Karen. She also pays a private carer to help her with household tasks and to take her to the shops where she uses a frame to help her get around. She attends the day centre three times a week and has recently joined the local church luncheon club where she enjoys meeting new people. She takes great pride in her home and tries to maintain it as best she can, remaining as

independent as possible. However, her lack of mobility means that she becomes frustrated at times when she cannot take care of herself or her home as she would like. She has strong relationships with regular carers although their timekeeping can sometimes mean she is late for the much needed visits to the day centre.

Lionel

Lionel is an 84 year old man living with his 82 yr. old wife. He has had a stroke and cannot walk unaided. He has carers visiting four times a day to help him get washed, dressed and go to the toilet, and they prepare his meals and prompt for medication.

His wife was in attendance at both the biographical-narrative and the follow-up interviews, and made comments throughout. Lionel has strong family support (two sons, one daughter and several grandchildren). One son, who lives locally, manages his finances and takes over what Lionel regards as the difficult task of form filling. The other son and the daughter live over two hours' drive away. They have practical support from family with shopping once a month but Lionel's day to day care is the responsibility of the carers. Lionel's wife struggles, and on both visits she broke down in tears feeling the strain of looking after Lionel. She said she felt she had no life. I detected Lionel's wife may be in the early stage of dementia and I my reflective notes recorded my concern about Lionel's welfare should her health deteriorate. Whilst the carers come in four times a day, he relies very much on his wife's emotional support and the strength of the home routines that she keeps going. Lionel visits the day centre once a week which gives his wife a break, however Lionel dislikes going to the centre as he finds it too disorganised and the activities too child-like. However, he continues to attend as he knows it gives his wife some respite.

The greatest concern that Lionel has is the feeling of loss of control of this life. He has been a saver all of his life and takes great pride in the fact that he has never been in debt and has managed his finances with great care. However, his savings are now very much depleted as they are being used to pay for his care. He feels extremely disgruntled about this. He also finds the form filling extremely taxing, hence the son's involvement.

He has recently changed to a different care company, a small, family run business that he seems to value highly. He reports how their timekeeping is far better and they always keep him informed about any issues. Lionel prides himself on his sense of duty and good manners and expects the care company to be the same. However, the old agency used to leave him

feeling stranded, sometimes turning up at 10 am after he had been in bed since early evening. He has to use a pad for the night time and feels a loss of dignity and control when he is left this way. What irritates him most is the lack of communication from the care company. If he is told when they are going to be late he would feel less aggrieved.

Pauline

Pauline is an 85 year old lady living alone having been widowed for 30 years. She has one daughter and one granddaughter neither who live close by. However, Pauline is a confident user of her laptop and keeps in close touch with them using Skype and Email. She also uses the laptop to keep abreast of current affairs and enjoyed exploring with me latest worldwide events. She also uses her laptop to order and arrange delivery of her weekly food.

She suffers from osteoporosis which affects her mobility. She has poor vision and has frequent falls resulting in broken limbs. Carers visit daily to help her with household tasks, doctors and hospital visits, and with personal care when she is recovering from falls. The same carers have been attending for nine years and she has formed strong relationships with them all.

She is a keen artist and takes pride in showing me her new paintings. She is also very proud of her cat and her pet tortoise and takes great enjoyment from feeding the hedgehogs in the garden. She attends the day centre twice weekly where she has made some strong friendships. Between my first visit (for the biographical-narrative) and my second, to collect the diary, she had fallen ill with a chest infection and she told me how frightened she was at being so isolated. She worries about the future and her vulnerability and spoke about how she had prepared her Will and that she wanted to ensure her daughter and granddaughter were well provided for. Even though Pauline is a positive, determined lady she is also obviously worried about how she would cope alone if she were to fall ill again.

Sadly, I heard during a day centre visit that Pauline died just a few months after my last visit.

Maud

Maud is a 92 year old lady who lives alone and has been widowed for 20 years. She has one son who lives locally who visits daily to make sure she has everything she needs. Maud has limited mobility due to issues with her legs and her back and has frequent falls. She also has limited vision and carers visit three times a day to help with getting in and out of bed,

washing and dressing and preparation of food. She attends the day centre twice weekly where she has developed some strong friendships, and she attends another monthly social club. She enjoys the company of the regular carers and relies heavily on their visits as it alleviates feelings of isolation. When I visited, Maud was sat in her chair overlooking her garden and she expressed sadness that her onetime hobby of gardening was now beyond her physical capabilities. However, she enjoyed telling me tales of the new hobbies she has taken up since joining the day centre and her monthly club.

Davina

Davina is a 71 year old lady who lives alone, having been divorced from her husband for ten years. She had a stroke at age 61 which left her paralysed down her left side. She cannot walk without support and uses a wheelchair whenever anyone takes her out. Her house has been adapted to meet her needs including a wet room, grab rails and her bed is in the lounge so that she does not have to use the stairs. Her son lives locally and visits regularly and manages her financial affairs.

Carers visit three times a day to help her get in and out of bed, get dressed and toileted. They also prepare Davina's meals. She often has different carers visiting and she seemed to have no strong connection to any one carer. She said she often felt uncomfortable with new carers especially if they were men when it came to her personal care. She attends the day centre once a week where she takes the opportunity to have a bath with support from the staff. A support worker attends each Sunday to take her out to the park or swimming.

Davina explained that she suffers from depression and that this is probably brought on by extreme loneliness she feels. She spends much of her time looking out of the lounge window having at passers-by hoping for some company. She told me she “hated her life”.

Eva

Eva is 92 years of age. She lives alone since divorcing from her husband. She has a daughter, a son and two grandchildren. She has a heart condition and type 2 diabetes. She suffers from leg ulcers and a nurse visits daily to bandage her legs. Carers visit daily to help her to wash and dress and they prepare her meals and prompt her to take her medication.

She attends the day centre three days a week.

When I arrived, the carer had just left Eva and she appeared agitated. She complained that the carer had not followed the care plan and had not helped her to have a bath as she had requested. She was also disparaging about the carers who were often late for her visits. Her daughter then arrived and explained that the relationship between Eva and her carers was not a happy one and that Eva regularly became angry with carers who would not do as she asked. Eva's home is in a rural location and her daughter explained that carers would often have to travel many miles to reach her and they struggled to be exactly on time.

Paul

Paul is an 86 year old man who lives with his wife of forty years. Approximately a year before my visit Paul suffered a fall and broke his hip. He was recovering and had just started to walk with the aid of a stick when he had another fall breaking his back, approximately six months before my first visit to his home. At that time he was diagnosed with Ankylosing Spondylitis, an inflammatory condition that affects the joints in the spine and little could be done to repair his back. Since then he has been confined to his bed in his bedroom. Furthermore, since then he has suffered a stroke leaving him with dysphasia and impairment of speech and verbal comprehension.

When I visited, Paul was able to communicate about his care with support from his wife. Together they explained that carers visit four times a day to wash and dress him and manage his toileting as he wears an incontinence pad 24 hours a day. They also prompt his medication and prepare his food. A district nurse also attends daily to ensure his pain is managed. A carer also attends each night to stay with him until the morning carers attend. He remains in his bedroom watching TV and his wife reads to him.

Sadly, just a few months after my visit, his wife contacted me to inform me that Paul had died.

Margaret

Margaret is 73, and lives alone, having been divorced from her husband for many years. She has type 2 diabetes but she also suffers from osteoarthritis and, following a removal of a spinal disc, she is in constant pain. She tires easily since she takes morphine daily to manage this pain. Carers visit five days a week to help her to manage her home, to help with food preparation and visiting doctors etc. She has had the same carers now for many years and has

formed strong relationships with them. They are familiar with Margaret's daily routines, prompting her to wake up for the day when she struggles with effects of the morphine.

In her earlier years, Margaret had a successful career and now struggles to accept the changes in her life as she lacks the confidence she once had. The morphine helps to manage her pain but she explained how it had affected her ability to engage socially as much as before and how this has impacted on her self-esteem.

Vera

Vera is 67 years old. She is divorced and lives alone. She had one son who is severely disabled and living in a residential care setting. Vera had a stroke many years ago which left her paralysed on her left side. She also has type 2 diabetes and has leg ulcers that need regular dressing. She is unable to walk without support and carers visit three times a day to help with washing and dressing. They also prepare food and prompt for medication.

She attends the day centre three times a week where she enjoys the company of others. She said that friends and neighbours visit regularly but she said that in spite of this she still feels isolated and lonely and suffers from depression. In spite of the support she receives, Vera appeared vulnerable. She was unclean and smelt of urine and her home was sparsely furnished and dirty. She was also confused about who attended to her needs as friends and volunteers and who was a paid carer. She also explained how money had been stolen from her purse by visitors to her home.

Ellen

Ellen is a 92 year old lady who lives with her daughter. She has a heart condition with means she has limited mobility and suffers from frequent falls. Before my visit she had attempted to go on the bus into her local town and had fallen to the ground at the bus stop. She had cuts and bruises on her face yet she was determined to continue with her normal daily routines. Ellen spoke of her resilience and resolve and how she attributes that to her earlier life experience in the armed forces.

Carers visit once each day to help her to get up in the morning and they prompt her to take her medication. However, Ellen told me how she felt vulnerable as each day she would not know which carer would be entering her home. However, she acknowledges the need for these carers.

She visits the day centre three days a week where she enjoys the company of others, but apart from that Ellen spends much of her time at home.

Sarah

Sarah is 72 years old. She has lived with her parents all her life but recently her mother died and now she lives alone. Her sister lives nearby. She suffers from leg ulcers and is unable to walk far without support. She is also waiting for a knee replacement operation.

A nurse visits daily to change her dressings and carers visit three times a day. They help her to get in and out of bed and to get washed and dressed. They also prepare Sarah's food and prompt her to take her medication.

She visits the day centre three times a week but Sarah explained that she gets lonely at home on her own having always lived with her parents and how much she values the company of her carers.

Gillian

Gillian is 90 years old. She lives alone, however her son and a daughter visit regularly to help her to manage her home and they take her shopping. She has had a hip replacement and struggles to walk without support. She spends much of her time at home but does visit the day centre twice a week where she enjoys the company of others.

Carers visit each morning to help her get out of bed and washed and dressed. They also prepare breakfast but Gillian is able to make her own food through the rest of the day. She has a positive relationship with her carers and she said that it is, on the whole, the same regular carers that attend. Gillian appeared physically fragile and vulnerable yet she was a very forthright lady. She was extremely direct and adamant that if anything was wrong with the care she received she would not hesitate to contact the care agency registering her discontent.

Violet

Violet is a 90 year old lady who lives alone. She is widowed and is registered as blind. Her daughter-in-law was present during the biographical-narrative interview to support Violet.

Violet has been widowed four times and her last husband died of a heart attack in her presence five years ago. Because of her blindness, Violet often suffers from falls and needs to

be accompanied whenever she leaves the home. She also struggles to manage indoors and needs help from carers to get in and out of bed and washed and dressed. She also struggles to prepare her own food and they help her with this, visiting three times a day. Violet is also incontinent and needs to wear a pad throughout the day and night. She does suffer from recurring sores that need to be well managed by her carers.

She has a very supportive family with her son and daughter and their partners helping her on a daily basis. Her granddaughter visits each weekend to clean her grandmother's home.

Her daughter-in-law explained that in the past the carers had not always been good. They left Violet without food and left objects in places where she may trip. They also failed on many occasions to help Violet to shower leaving her unclean and more susceptible to sores and infection. Recently, however, new carers have been attending and both Violet and her daughter-in-law said how successful the new arrangement is.

APPENDIX 7

Extracts from reflective journal

Extracts from reflective journal

1. Background to reflections recorded on 20th May 2014 and 20th June 2014 (Pauline):

I received a telephone call from Pauline an 85 year old lady, in response to my article in the Independent Age magazine “Golden Link” requesting participants to my study. She was keen to talk to me about her care and I arranged to visit her to introduce myself, explain the study, gain consent and carry out the biographical-narrative interview. When I arrived she had baked a cake and made a tray of tea for us and she seemed very excited about my visit. She talked about her past and revealed information about her husband’s death and her subsequent suicidal feelings. She also talked about how she struggles with the isolation now that she lives alone. We then talked about her care now, how it supports her independence and how her carers were more like friends. I then visited twice more, and on each occasion she welcomed me warmly into her home and opened up more about her life, her hopes and her fears, even talking about her funeral plans and writing her Last Will and Testament. When I left, after the first meeting I recorded the following thoughts in my reflective journal:

Reflection 20th May 2014

*I am just so amazed at how willing Pauline is to talk to me about the most intimate and personal details of her life. Whilst I know that it is really important to develop a rapport so that she is able to share, I am concerned she may want to enter into a friendship and I know that goes beyond my remit as a researcher. I feel Pauline may develop some sort of emotional attachment to me which I know I will have to manage. I worry how she will feel when I finally leave. Will she feel abandoned? Yet when she cried about her husband I held her hand in support. Did I overstep the mark and I am contributing to the blurring of the boundary between me as a researcher and me as a 'friend'? What is appropriate researcher conduct in this regard? I must prepare Pauline for the ending of the study and let her know there will come a time soon when I will have to say goodbye, yet I am not sure how I will do this. **Things to think about and to read up about: Research ethics/relationship between researcher and participant/preparing for endings***

When I visited the second time to collect the diary, again Pauline was very excited to see me. I had reflected on my earlier visit and the concerns I had about her expectations. When she asked me about how the study was progressing I mentioned that once I had collected data from all participants I would be entering an intense stage of data analysis and I would be very much confined to my office. I felt this was a gentle way of preparing her for the ending of my visits. When, at the end of the final visit I said goodbye, she asked me if I would visit her

again, if only at the day centre. I reiterated that I would be immersed in the analysis but there was a good chance I would be visiting the day centre again and I hoped we could have a cup of tea together. She seemed happy. Sadly when I returned to the day centre three months later to talk to another prospective participant I discovered Pauline's on-going chest infection had developed into pneumonia and she had died. I felt extremely sad and also rather ashamed that I had not managed to keep my word and see her again. I wrote in my journal:

Reflection 20th June 2014

*At times I feel uncomfortable in this role as researcher. In sharing such intimate details, Pauline had allowed me into her life. Did I think carefully enough about the implications and the consequences of doing that? Did I let her down? Now, when I interview other participants, on one level I feel I must maintain the boundary more carefully but then again, if they speak about their lives, how is it possible not to show care and concern? This is such an incredible responsibility, and out of respect for Pauline I have to do something worthwhile with her story and I really feel I would be letting her down if I did not. I still feel a huge sadness that she has died and I think it is a feeling that will stay with me for some time. **Things to think about and to read up about: relationship building between cared-for and carer/isolation***

These two reflections made me think about my "presuppositions, choices, experiences, and actions during the research process" (Mruck and Breuer, 2003, p. 3). I thought more carefully about managing boundaries (Dickson-Swift et al, 2006), although I found it equally difficult with subsequent participants and it felt wrong not to engage in a warm friendly manner. I did make a more conscious decision to gently prepare participants for the time I would be saying my final goodbye (Boynton, 2005). I also thought about Pauline's comments about her strong relationship with her carer and what a crucial role a carer can potentially play in the life of someone, like Pauline, who is in need of companionship.

2. Background to reflections recorded on 6th June 2014 and 30th June 2104 (Clare):

I was introduced to Clare, an 82 year old lady at her local day centre. She was interested in my study and she invited me to her home so that she could participate. When I arrived at her home I was shocked by her living conditions. She was confined to her chair in the lounge, being unable to stand or walk unaided. She had a catheter with an almost full bag by her side. Both Clare and her home appeared unkempt and it was clear she was dependent on others for many acts of daily living. During the biographical-narrative interview Clare spoke positively about her care yet she recounted incidents of care that were negligent. She explained that often carers would arrive at her home exhausted and would use the time allocated for care to

take a nap. When I asked her how she felt about this she knew it was wrong, particularly since she was so dependent on care, but she would not challenge either the carers or the care organisation. When I probed into why she did not speak out, she said she was worried it would affect her care and because she liked the carers and did not want upset them. When I left I recorded the following thoughts in my journal:

Reflection 6th June 2014

*I feel so sad for Clare. I just feel she is not receiving adequate care. During the meeting I was worried about the catheter bag level and wondered when the carer would be calling next. But why does Clare not speak up when care is not as it should be and when carers fall asleep? Not only is she missing out on crucial personal care, but if they have time to spare why don't they spend it engaging with Clare? She seems so lonely and the carers are usually the only people she sees from one day to the next. I know my study does not focus on quality of care but rather on how self is considered during care, but it is hard to ignore possible neglect such as this. However, with regard to self, I wonder how much Clare's autonomy and dignity is being respected and if carers recognise and acknowledge that Clare is an individual with her own wants and needs. **Things to think about and to read up about: speaking out when things are not right/isolation***

Four weeks later I returned to visit Clare to collect the diary. She was pleased to see me but she was clearly embarrassed that she had not been able to write in the diary. She explained that the carers had seen the diary, told her she did not need to complete it and removed it, out of her reach, to the other side of the room (she was unable to stand or walk without their support). When I asked how she felt about this, she explained that she was cross with them but had not challenged them, again as she did not want to upset them. I reassured her that I was not concerned about the diary. When I left I recorded the following thoughts in my reflective journal:

Reflection 30th June 2014

I am so disappointed Clare did not complete the diary. I feel a little embarrassed that for one moment I was concerned about a lost chance to get another diary account. I must challenge my thinking in this regard and focus on Clare's circumstances. However, my biggest concern is that Clare so wanted to complete the diary and yet she was denied this opportunity by the carers. I feel both disappointed and sad. Disappointed because the carer had taken away Clare's autonomy and sad because Clare did not feel able to assert herself and ask for the diary back.

Things to think about and to read up about: speaking out when things are not right/autonomy/researcher involvement

These two reflections around Clare's care made me focus my reading on the issue of autonomy. I explored the difference between decisional and executional autonomy and how both are realised in care (Collopy, 1995, Boyle, 2005, Sykes and Groom, 2011). I saw that Clare's executional autonomy was extremely limited due to her lack of mobility, yet she was fully capable of making decisions and having control over her life. As I progressed through the interviews and analysis for other participants I recognised that autonomy was a recurring theme, and Clare's loss of control was typical for many others.

3. Background to reflection recorded on 11th September 2014 (Susan):

I received a call from Susan's husband saying that she had seen my article in the Independent Age magazine "Golden Link" requesting participants to my study and was keen to participate. Susan is a 72 year old lady with health and mobility issues that mean she spends 24 hours a day in her chair in the lounge. When I visited Susan I was invited by her husband into the lounge to take a seat next to Susan who was, as always, in her chair. She was surrounded by personal belongings including clothes, books, magazines and she had her catheter bag between her chair and the chair I was asked to occupy. I realised very quickly that this was Susan's lounge and bedroom and permanent living place. I felt uncomfortable intruding into such a personal space and I recorded my thoughts and feelings in my reflective journal:

Reflection 11th September 2014

I feel I was such an intruder as I entered Susan's personal space today. This room constitutes her entire world and I feel so humbled that she invited me in. I hope I was respectful and gave Susan and her personal space due regard. Whilst she seemed happy to speak to me, because of the sensitivity around her environment I must make sure, before I return, that she is still happy to continue taking part in the research. This has made me think more about home and what it means to older people receiving care at home. I would hate it if my home was 'invaded' by others and that's how I think it would feel for me – an invasion. I don't know if Susan feels this way but I must be sensitive to the fact that she might.

Things to think about and to read up about: Value of home for participants/researcher involvement

This reflection around Susan's home environment focused my reading on the potential for home space to be transformed into a care space and how this impacts on an older person's sense of self (Healey-Ogden, 2014). I thought about the participants I had already met and recognised similar transformations and I resolved to consider the possibility of this for participants I was yet to meet. I also thought about the sensitivity of researchers towards

participants' circumstances and how I could ensure I managed my role so that I showed due respect and regard (Mitchell and Irvine, 2008).

APPENDIX 8

PRISMA flow chart

PRISMA flow chart

