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Exploring care relations in later life: disentangling notions of care and choice.

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Doctor of Philosophy

ASTON UNIVERSITY

September 2015

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Aston University

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The experience of later life varies widely and is often framed in terms of the active lifestyles of the Third Age and the frailty and abjection of the Fourth Age. This thesis sought to understand how the concepts of care and choice are enacted, experienced and interrelated in the context of both informal and formal care in later life and how older people themselves, their families and significant others understand and experience these concepts. The discourse of personalisation that dominates care services has led to an emphasis on individual choice, control and independence so that those in need of care are faced with what has been described as the 'logic of choice', a focus on individual responsibility rather than care. Adopting a Feminist Foucauldian theoretical approach and drawing on Tronto's (1993) ethic of care, this thesis explores the experiences of older people and their informal carers through dialogical narrative analysis. The stories begin with the recognition by individuals that there is a need for care and how this need is met through negotiations with families and significant others. As needs increase the physical and logistical limits of informal care by individuals are reached, often leading to a need to 'choose' formal care. Rather than impacting solely on the care recipient, formal care is shown as being an experience that is shared with informal carers. Indeed, the participants depict how informal care continues alongside formal care and how the boundaries between them become blurred. I argue that a binary division between actively making choices and being a passive recipient are not appropriate to understandings of care. By disentangling the notions of care and choice this thesis explores the extent to which these concepts are relevant to the experience of older people in specific care situations.

Keywords: Ageing; Ethic of care; Care relations; Personalisation.

Acknowledgements

This studentship was supported through the Aston Research Centre for Healthy Ageing (ARCHA).

I am grateful to ARCHA for funding this research and to everyone at Aston University that has supported and encouraged me through my studentship. Particular thanks to my supervisors Dr Karen West, Dr Carol Holland and Dr Katy Pilcher for their encouragement, support and guidance. I would also like to thank my participants for allowing me to hear and re-tell their stories. Final thanks go to my family for their constant support through this process.

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Chapter One: Introduction

As we move through life many of us wonder what will happen when we get old and are no longer able to cope on our own. It is difficult to view later life from earlier in the life course; we look at our older relatives and cannot imagine how life will be when we reach their age. We may ask ourselves who will care for us and how our journey into care will unfold. This thesis asks how older people experience care, whether that is informal care provided by family and significant others or formal care provided by paid carers in the home or in an institution. In modern Western societies social policy is influenced by neoliberal ideas of individual responsibility and personal choice. In this context, how are understandings of care and choice connected?

In discussions of later life, the use of appropriate language needs careful consideration. The concept of age is both a social construction and a corporeal experience. Retirement age is closely linked to discussions about later life but chronological age does not necessarily correlate with care needs. This thesis draws on the concepts of the Third and Fourth Age introduced by Laslett (1991) and discussed extensively by Higgs and Gilleard (2014; 2015). Discussions of ageing begin with the dilemma of what language to use to refer to aged individuals. The phrase 'older people' is argued to be a more inclusive and less ageist phrase than 'elderly': there is no identifiable point at which a person becomes elderly, they merely become older (Bytheway, 1995:125). However, Calasanti (2003) makes the point that:

“while the term ‘old’ is stigmatized, so are many other terms for oppressed groups, using the term ‘older’ conveys that the old are more acceptable if we think of them as more like the middle-aged. In much the same way that many would find it ludicrous to refer to Blacks as ‘darker’ and instead recognize the efforts to reclaim the word ‘Black’ and imbue it with dignity.” (Calasanti, 2003:16)

While I agree with Calasanti's position, I will use both 'old' and 'older' throughout this thesis. I feel that to use the word 'older' is appropriate in theoretical discussions of ageing where that phrase is widely agreed to be the accepted term. The participants in this study were a mix of relatives and significant others who had arranged care for older relatives and older care recipients themselves. In common with Jones (2006:29), I found that my older participants used the term 'older' to describe their peers or themselves and usually used the term 'old' to indicate someone who is different to themselves or to denigrate their situation or opinion. When discussing the period of later life when individuals would be considered by others as 'old' then the term 'real' old age will be used. 'Older' is more suitable for a person whereas 'real' old age is a more appropriate reference to a period of the life course.

The concept of 'real' old age is closely linked with the need for care and this thesis draws on Tronto's (1993) feminist ethic of care and its view of care as part of all human relations. It seeks to explore the experience of older people who find that they need not only the help and support of their families and significant others but, as their needs increase, they also need formal care, either in their own home or in a residential care home. This exploration is undertaken through discussions with older people but also with families and significant others who have arranged care for an older person.

The overarching aim of this thesis is to understand how the concepts of care and choice are linked together and to explore whether disentangling these notions provides us with a clearer view of the experience of arranging care for older people. The experience of arranging care for older people involves not just the older person themselves but their families and significant others and so to fully understand the context in which care choices are made the experiences of both older people and their families and significant others are considered. The discourse of choice heavily influences policy on social care and this research seeks to explore the extent to which the emphasis on individual choice is reflected in experiences of giving and receiving care in the context of later life. The thesis draws on the theoretical concept of the Fourth Age as it is currently framed by Higgs and Gilleard (2015). The Fourth Age is a social imaginary, a shared view of 'real' old age that exists in contrast to the cultural field of the Third Age. The Third Age allows for a multiplicity of experiences and active pursuit of fulfilling lifestyles whereas the Fourth Age is fashioned by discourses of frailty and the powerlessness of those unable to adequately maintain their connection to the world (Higgs & Gilleard, 2015). Taking a feminist Foucauldian theoretical approach, I argue that the concept of individual choice has become so strongly associated with care that it has become impossible to conceive of good care in other terms. While this discourse fits with the agentic period of the Third Age, for those who find themselves 'at the intersection of old age and impairment' it would seem less appropriate (Grenier & Phillipson, 2013). This is not to say that choice is not valued by older people, but it is the aim of this thesis is to explore the extent to which the emphasis on individual choice is relevant to the experience of older people in specific care situations.

Thesis Structure

The thesis begins with a literature review which sets out understandings of ageing and the approaches to later life that are adopted throughout the later discussions of older people's experiences. It explores the structural influences on later life, the concept of governmentality and the policy approach to the personalisation of care services and the associated emphasis

on individual choice, control and independence. Current understandings of the nature of care of individuals are explored and are contrasted with the Tronto's (1993) theory of the ethic of care which argues that care is based on relationships between individuals and the world around them. The ethic of care leads to discussions of autonomy of individuals in contrast to relational autonomy, where people's actions are understood by considering the roles of social norms and cultural practices. This is in contrast to views of autonomy that suggest that individual's actions are undertaken independently of social context. These discussions lead to further examination of the concept of agency which is defined as the capacity to exercise choice and discusses how research based in psychosocial approaches can provide a framework that accommodates the contradictions of everyday experiences. Having explored the context of choices, the way in which the process of choice is understood in healthcare and social care are discussed. Healthcare decision-making models provide a view of the sharing of information and personal preferences in situations where there is an imbalance of knowledge and power. The process of social care explores the issue of finding and using information further but does not explore in detail the way in which this information may be shared between services users and those who care for them. The literature concludes with the understanding that the concepts of care and choice are influenced by power relations and that to understand how care is experienced by older people it is necessary to explore how these concepts are entwined.

The third chapter describes the theoretical position of the thesis and sets out the process of the research design. The research began with a commitment to undertake face-to-face interviews with older people, families and significant others who had experience of arranging care for themselves or an older relative. An initial focus group study was undertaken to gain an understanding of the broad concerns and provide direction for the fieldwork. The findings from this focus group indicated that the interviews should not be highly structured but should be conducted in a way that allowed participants to discuss the experiences that were important to them and to frame them in their own way. The interview participants included older people who were receiving care, older people who cared for their spouses and relatives who had provided or arranged care for older family members. The interview data were explored through narrative analysis. The narrative analysis undertaken here draws on dialogical narrative analysis (Frank, 2010) and seeks to represent the stories of the participants whilst acknowledging that their stories are not finite and that they continue beyond the narratives discussed here.

The narratives are presented in three empirical chapters that follow care narratives from the initial evolution of relationships that become care relationships, through the 'choice' of formal care to understandings of care practices and understandings of the Fourth Age. The first empirical chapter, Chapter Four, draws on Bowlby et al's (2010) concept of 'caringscapes' as terrains through which a journey of care is navigated. It explores the ways in which family relationships evolve into care relationships and how informal care develops and accommodates the changes in the older person's needs and emphasises the relational nature of care.

Chapter Five explores the limits to informal care and the transition to formal care and describes how decisions about formal care vary between situations where there is time to prepare for the transition and situations where sudden illness requires urgent action. The ways in which care recipients navigate and sometimes resist the transition are examined. The impact of interactions with care professionals on care experiences is also discussed. Chapter Six considers the role of informal care as it continues alongside formal care, considering the changes that the informal carer faces in 'letting go' of their care role, and the extent to which they are able to continue to maintain their carer relationship with their relative or significant other in long term care. This chapter also considers the difficulty faced by care recipients who feel that they are regarded as problem parts such as a broken leg rather than a whole person.

The thesis contributes to wider discussions of care in later life by exploring the role of choice in the way that older people experience both formal and informal care in later life. The thesis seeks to provide a view of the way in which 'care' and 'choice' are combined within older people's experiences.

Theoretical Perspective

The position taken in this thesis is that an 'objective' view of the world is not possible; instead, following Haraway (1988), it is necessary to *situate* our knowledge. This means that we should recognise that our view is limited and embodied. Haraway (1988:589) argues for the epistemologies of location, positioning and situating where partiality is the basis for knowledge claims. Haraway (1988:582) draws on an edition of National Geographic that contrasted the scientific view of outer space and the universe with an 'inner view' of sciences that explore individual cells and invading viruses. The perspective of both the macro and the micro suggest an infinite vision that can contemplate the vastness of space and the minutiae of individual cells in one glance, a view that Haraway (1988) calls a 'god trick' which "promises vision from everywhere nowhere equally and fully" (Haraway, 1988:583–584). However,

Haraway argues that the view of space is the privileged view of the powerful and suggests that there “is good reason to believe vision is better from below the brilliant space platforms of the powerful” meaning the view from the perspective of the subjugated.

Haraway (1988:585) argues that there is a danger in appropriating the view of the vantage point of others as we cannot ‘be’ all of the things that we wish to study. She suggests that “mobile positioning and passionate detachment” provide a strategy for seeing the standpoint of the subjugated through the understanding that one cannot relocate to see from someone else’s position without accounting for that movement (Haraway, 1988:585). The relocation to another perspective is possible as Haraway (1988) argues:

“the knowing self is partial in all its guises, never finished, whole, simply there and original; it is always constructed and stitched together imperfectly, and therefore able to join with another to see together without claiming to be another” (Haraway 1988:586).

The idea that we cannot become another person but can only represent their perspective is discussed further in the later section on the importance of representation. Feminist concerns about objectivity relate also to concerns about the status of an ‘object’ of knowledge being passive and inert. As such these objects can be seen as masks for dominating interests; here Haraway (1988:591) uses the example of ‘sex’ as an object of biological knowledge. Viewing ‘sex’ as an inert object prevents active and transformative interventions which are allowed within feminist concepts of gender as a “socially, historically and semiotically positioned difference” (Haraway, 1988:591). To lose the biological accounts of sex would mean that we also lose the tensions between sex and gender, leaving the body as a blank page for social inscriptions (Haraway, 1988:591). Haraway (1988:592) suggests that the object of knowledge should be pictured as an actor and agent, active rather than passive. This ‘activation’ then problematises binary distinctions like sex and gender, without eliminating their utility (Haraway, 1988:594).

In arguing for situated knowledge, Haraway (1988) urges researchers to articulate the position from which they view the world, to acknowledge how they move from that position to see from another’s position without claiming to be a different person. In this way we can acknowledge our partial view and situate our knowledge claims in their historical and local position.

In common with Haraway’s (1988) exploration of scientific objectivity, the work of Foucault also explores the relations between objectification, subjectivity and social practices (Rabinow,

1984:4). Foucault's work seeks to create a history of the ways in which, in Western culture, human beings are made subjects. He explores this through three modes of 'objectification of the subject' (Rabinow, 1984:7). The first of these modes is 'dividing practices' whereby the "the subject is objectified by a process of division either within himself or from others" (Rabinow, 1984:8). 'Dividing practices' are essentially practices that divide people by combining the mediation, or influence, of a science (or pseudo-science) and the practice of exclusion, usually in a spatial sense but always in a social one (Rabinow, 1984:8).

The second mode for turning human beings into objectified subjects is 'scientific classification.' The conventional view of knowledge, particularly scientific knowledge, is that it is created by a series of isolated creative geniuses. For example, Einstein and Pasteur are characterised as exceptional people who were able to transcend the conventional ideas of their period and formulate completely new ideas and theoretical perspectives (Mills, 2003:67). Foucault argues that the knowledge is linked to power and uses the phrase power/knowledge to indicate that "it is not possible for power to be exercised without knowledge, it is impossible for knowledge not to engender power" (Foucault, 1980 cited in Mills, 2003:69). Foucault characterises power/knowledge as an abstract force which determines what will be known rather than assuming that individual thinkers develop ideas and knowledge. It is not the scholars that work unceasingly to improve on past knowledge instead it is power/knowledge which produces facts and scholars are just the vehicles (Mills, 2003:70). Foucault focuses on the mechanisms by which knowledge comes into being and argues that these are "institutionalised and rule-governed" models of knowledge-production (Mills, 2003:68). Where there are imbalances of power relations between groups of people or between institutions there will be a production of knowledge. An example of this would be the institutionalised imbalance in power relations between men and women in Western countries and Foucault would argue that because of this more information is produced about women; thus we find many books in libraries about women but few about men (Mills, 2003:70).

Foucault argues that rather than knowledge being a pure search after 'truth', power operates in the processing of information resulting in something being labelled as a 'fact', for something to be considered a fact, it must undergo a thorough process of ratification by those in positions of authority (Mills, 2003:72). This process of ratification takes place through discursive practices which are discussed in the later section on the importance of representation but can be summarised by considering discourse as an overall term that refers to all statements, and the rules whereby those statements are formed, with discursive

practices being the process whereby some statements are widely circulated and other statements are excluded or suppressed (Mills, 2003:62).

Foucault's third mode of objectification is 'subjectification' and concerns the "way in which a human being turns him- or herself into a subject" (Rabinow, 1984:11). The dividing practices are techniques of domination where the person being classified or separated is seen as being in a passive, constrained position. In contrast, in considering 'subjectification' Foucault looks at processes in which the person is active and the techniques through which the person initiates an active self-formation (Rabinow, 1984:11). Whilst these techniques of the self involve the individual actively shaping the self, they are still considered disciplinary practices and these practices are explored in depth by Bartky (1990) in her discussion of the ways in which women "undertake the disciplinary project of femininity" (Bartky, 1990:72).

Bartky (1990:79) discusses how in modern societies, effects of power "circulate through progressively finer channels, gaining access to individuals themselves, to their bodies, their gestures and all their daily actions". Power seeks to transform the minds of those individuals who might be tempted to resist it rather than to punish or imprison their bodies. To do this, society requires control of the body and its movements but this control cannot be achieved without ceaseless surveillance (Bartky, 1990:79). Foucault's (1977) book "Discipline and Punish: The birth of the prison" deals with the rise of the prison and the novel form of punishment of criminals that accompanied it. In pre-modern times, the retribution for crimes was enacted on the criminal's body whereas the introduction of continuous surveillance allows the retribution to be enacted on the mind (Bartky, 1990:66). Foucault argues that only a particular mode of society could have invented this form of punishment (Bartky, 1990:66). Panopticism is the technique through which disciplinary power is able to function; it relies on a method of 'surveillance' originally discussed as an architectural design by Jeremy Bentham (Foucault, 1977:200). The Panopticon involves a circular building around a central space; at the centre is a tower with wide windows that open onto the inner side of the ring. The outer building is divided into cells which reach across from the front to the back of the building. Each cell has two windows, one on the inside, corresponding to the windows of the tower; the other, on the outside, allows the light to cross the cell from one end to the other to ensure that the occupant can be seen easily. A single supervisor is then able to observe from the tower each person in each cell (Foucault, 1977:200).

Foucault (1977:206) explains that the Panopticon gives the 'power of mind over mind' and can be integrated in to any function (education, medical treatment, production, punishment). This

new mode of control allows the exercise of power to become faceless, centralized and pervasive (Bartky 1990:79). Knowing that he may be observed from the tower at any time, the inmate takes over the job of policing himself. The gaze which is inscribed in the very structure of the disciplinary institution is internalized by the inmate: Modern technologies of behaviour are thus oriented toward the production of isolated and self-policing subjects (Bartky, 1990:79).

Bartky explores this further by examining the disciplinary practices by which the ideal body of femininity is constructed and whereby a 'practised and subjected' body is produced, that is, a body on which an inferior status has been inscribed (Bartky, 1990:71). Bartky (1990:67) explains that there are significant gender differences in gesture, posture, movement and general bodily comportment. Women tend to adjust their posture to take up little space whereas men expand into available spaces; women tend to take smaller steps than men and will cast their eyes downward rather than staring around (Bartky, 1990:68). These disciplinary practices are self-movements that reflect the ways that women are trained to perform femininity. In a similar way, older people may consider certain ways of behaving as being 'age appropriate' and are concerned with 'growing old gracefully' rather than appearing as trying to look younger and behave younger than their years and being seen as 'mutton dressed as lamb' (Fairhurst, 1998:261). The use of disciplinary practices are important in this study of experiences of later life as the ageing body is subject to the surveillance of medicine and wider society to ensure that the individual acts appropriately for their age and responsibly to avoid excessive risk and to resist frailty and dependency.

Bartky (1990:69) describes how women must undertake practices to ensure that their skin is soft and betrays no sign of wear, experience, age or deep thought and hair must be removed not only from the face but from large surfaces of the body as well, from legs and thighs. This links to the anti-ageing practices of removing hairs sprouting from the nose, the ears or the chin that serve as signs of ageing and weakness (Higgs & Gilleard, 2015:82). The disciplinary power that inscribes femininity in the female body, and similarly that which denigrates the visibility of old age, is everywhere and it is nowhere; the disciplinarian is everyone and yet no-one in particular (Bartky 1990:74). Foucault identifies the imposition of discipline with the operation of specific institutions; however Bartky (1990:77) argues that this overlooks the extent to which discipline can be institutionally unbound as well as institutionally bound. She suggests that the anonymity of disciplinary power and the absence of a formal institutional structure and of authorities invested with the power to carry out institutional directives

creates the impression that the production of femininity is either entirely voluntary or natural (Bartky 1990:77). The ideas of institutionally unbound power and disciplinary practices are reflected in discussions of the power of the social imaginary of the Fourth Age which is also anonymous and institutionally unbound and provides a basis for the use of Foucauldian concepts as an appropriate theoretical approach for this research.

Crotty (1998:214) discusses whether it is appropriate to link research to an individual scholar such as Foucault and raises the question of how close one needs to be to Foucault to justify calling one's process Foucauldian. Crotty (1998:214) argues that a purist stance would "insist that we must apply to our area of research precisely and exclusively the approach that Foucault has enunciated." Foucault's works draw on Nietzsche's conception of genealogy, a process of exploring the past and rather than tracing a line of inevitability he seeks to break the past off from the present and demonstrate the differences of the past to the present (Sarup, 1993:58). This gap between the past and the present is used to demonstrate how knowledge production is not a linear process and that instead knowledge is local and discontinuous (Sarup, 1993:59). Crotty (1998:215) suggests that it is possible to be "more or less Foucauldian" and that there may be aspects of Foucault's work that we want to dismiss while other aspects are a useful way to explore the topics that we want to study. This research does not follow a Foucauldian method of genealogy but does draw on Foucault's conceptions of knowledge, power and discourse by exploring discourses about care and choice, and the power relations that exist between care givers and care recipients. In particular the discourse that choice leads to empowerment which leads to better care.

The preceding discussion demonstrated the theoretical position of this thesis. Firstly, that a researcher should recognise their partial view of the world and make explicit the situated nature of the knowledge claims being made. Secondly, that knowledge is linked to power and it is not possible for knowledge not to engender power. Finally, the discussion explored the ways in which power is exercised in modern societies through institutional and non-institutional disciplines and how subjectification involves individuals actively shaping their behaviour under ceaseless surveillance.

These understandings of power underpin discussions of care where the care giver is seen to be in a position of power over the care recipient and discussions of ageing where discourses of old age portray individuals as powerless. To understand how the concepts of care and choice are connected in the context of care in later life it is important to consider the impact of power imbalances within care practices. To fully understand this we need to ask older people,

their families and significant others about the experience of negotiating care and making care choices since their stories will be shaped by systems of power and power relations.

Personal Motivations

In taking a feminist Foucauldian approach, I recognise that the ways in which the knowledge produced in this thesis is 'socially located' (Haraway, 1991) as well as grounded in the participants' experiences. In line with previous important feminist explorations of research motivations, I would like to briefly explain how my interest in the experiences of later life developed. Before beginning in higher education as a mature student, I spent several years working as a gardener. For some older clients I was one of the few people that they would have regular interaction with and we developed friendships over the years; I would often stop for a coffee and chat after my allotted time. My initial impression of these much older people was that their lives were very different to the stereotypical portrayal of later life. They were not passive and disinterested; they were certainly passionate about their gardens. A client named Elizabeth had a 'handkerchief' garden; each plant had a story attached, a simple Hebe was a memory from a holiday in Cornwall where she and her husband had sneaked a cutting from their holiday cottage and that cutting was an irreplaceable shrub that needed careful tending, as she was now widowed and it served as a reminder of a happy time with her husband. Another client, Edward, was no longer able to walk as far as the end of his driveway but would stand outside the front door in spring and ask me whether I could see the bulbs pushing through yet or whether the weeds were vigorous this year. These people saw their gardens as a way of connecting with the outside world as well as keeping hold of the past. A friend of Elizabeth phoned me one week to say that Elizabeth would not need me anymore as she had been diagnosed with throat cancer and had refused treatment; she died within six weeks. Edward lived alone but one day his daughter phoned me to say that Edward had died in the night. The loss of these friends started me thinking about how the choices that we make in later life send out ripples that disturb the lives of our family and friends. It is because of these friends that I wanted to understand more about the way older people are portrayed in our society and how this contrasts with older people's experiences of later life.

The questions that this thesis seeks to answer are how do older people, their families and their significant others understand care and choice in later life? How does the policy emphasis on individual choice impact on decisions relating to formal care in later life? How does the concept of choice relate to the practice of caring? And does examining care activities improve our understanding of care choices in later life?

The literature review that follows sets out the academic discussions of ageing and the ways in which the central themes of care and choice are constructed to provide the view that good care is only possible when linked to individual choices.

Chapter Two: Literature Review

Introduction

The aim of this study is to understand the experience of ageing in the specific period of time when the functioning of the body and/or mind deteriorates, or is seen to deteriorate, to the extent that an individual requires support to carry out the day to day tasks of personal care, whether that is help with washing, toileting or eating. Given the current emphasis on choice in social care, these changes in ability give rise to situations where choices need to be made as to how, where and by whom this care support is to be given (Glasby & Needham, 2014). It has been acknowledged that choice in social care is about more than the care recipient, it also should consider the families and friends that support them (Glendinning, 2008:463).

The literature review begins by setting out the debates around the meaning of age and consideration is given to the importance of the ageing body before moving on to examine the way in which social policy has developed, how neoliberal influences have moved discourse on older people's care from the collective provision of services to individual responsibility. The literature review explores the personalisation of social care with its emphasis on choice and control. It then considers the meaning of care, how different approaches to the research of care focus on physical tasks, power relations, the public and private provision of care. The social relationships that are part of one person caring for another form the basis of Tronto's (1993) feminist ethic of care and this is contrasted with the ethic of rights which refers to individual rights and the rules that govern those rights. This discussion considers the view that care is not just about dependence or independence but more about relational autonomy. To understand relational autonomy in contrast to personal autonomy, the next section discusses the link between agency and choice. The process of choice in healthcare has been explored with the understanding that there is an imbalance in both power and knowledge when making treatment decisions and so individual choice is not always the most appropriate approach. The decision-making models describe how shared decision making in healthcare allows for both healthcare professionals and patients to be involved in making choices. The final section explores the ways in which the process of choice in social care has been discussed and raises the question of whether individual choice in social care is appropriate for all service users.

The literature review seeks to provide an outline of the contested meanings of age and care and the impact that changes in social care policy have on older people's opportunities to exercise agency in later life. It also aims to show that while we understand care as relational,

choice is often discussed as being exercised only by individuals. This thesis will contribute to an understanding of how choice is entwined with care and how these concepts can be considered in relation to one another.

Defining Older People

In order to explore the experiences of later life it is first necessary to set out what is meant by the term 'older people'. When discussing the 'problem' of older people, scholars and policy makers often speak of one homogenous group that includes everyone over the official retirement age (Coole 2012; Department of Health 2013). Statistical information about population ageing acknowledges that older people cannot be regarded as one cohort and often provides an age bounded category such as the 'young old', those aged over 65 (17% of the UK population in 2010) and the 'oldest old' those aged 85 and over (2% in 2010) (Office for National Statistics 2012). Despite this clarification the use of statistical information about the level of dependency of older people is argued to be misleading as the standard indicator is calculated by looking at the proportion of people over and under retirement age, and this does not take into account the large number of healthy retired people who continue to be active both as support for relatives and as volunteers within their communities (Spijker & MacInnes, 2013).

Rather than employing an age-based distinction between experiences of later life, Laslett (1991) introduced the terms the Third and Fourth Ages. These distinctions are not 'bounded by birthday ages' but relate to the argument that there is a difference between a fit, healthy and productive later life and an old age featuring ill health and incapacity (Higgs & Gillear, 2015:11). The Third Age is characterised by the desire to maintain, extend and even enhance indefinitely the capacities linked to the Second Age, the younger more 'productive' period of our lives (West & Glynos, 2015:4). These concepts were proposed to distinguish healthier groups of older people from those perceived as frail. The concept of 'Third Age' was meant to counter age-based discrimination by focusing on active healthy and productive aspects of ageing but has since been criticised for over-stating the positives of active ageing and defining as negative the illness and impairment of the Fourth Age (Grenier & Phillipson, 2013:57). Indeed, rather than a focus on positive aspects of ageing, the Third Age has come to stand for 'positive' ageing which has been criticised for an emphasis on anti-ageing strategies (Andrews, 1999:308), whilst the Fourth Age has become synonymous with illness and impairment, a state to be avoided.

Gilleard and Higgs (2013a) suggest that the Third Age is a cultural field that allows the 'young' old to follow a variety of lifestyles. The idea of an individual with a single fixed identity is replaced by the understanding that experiences are shaped by cultural settings and that those experiences are also differentiated by gender, sexuality, (dis)ability, ethnicity and age (Lister, 2010:106). Gilleard and Higgs (2013) argue that the possibility of multiple identities allows individuals to resist ageing, not by clinging on to youth but by retaining the virtues of identities: "staying 'black', staying 'gay', staying 'gendered' and staying 'disabled' in later life is not so much about clinging on to youth as it is about retaining the 'virtues' of these particular identities and their embodiment" (Gilleard & Higgs, 2013:166). This links to the notion of continuity that was originally proposed by Atchley (1989) to demonstrate how later life may be characterised by similar interests and activities pursued in earlier segments of the lifecourse. Grenier (2012:140) draws on this concept when exploring the transition to later life and suggests that illness and impairment constitute a threat to continuity and reinforce the difference between older people who are healthy and those who are ill or impaired. However, those with illness or impairments may adapt their activities in order to maintain some sense of continuity.

Taking a post-structuralist approach, the practices involved in retaining or maintaining these identities could be considered to be what Foucault called "technologies of the self" (Lemke, 2001), These technologies refer to practices that individuals apply to themselves, rather than those that are imposed by an external coercive force, because they believe it is in their best interests, having internalised the norms that those with power have established (Biggs & Powell, 2001:7). These norms are circulated through discourses of ageing and whilst older people are the subjects of power they are also agents of resistance who can mobilize action against discourses and, according to Foucault, "subvert the historically given conditions of their identity formation" (Katz, 1996:26). The possibility of this type of action from a position of 'real' old age is an important element of this thesis.

The understandings of the Third and Fourth Age are currently the subject of debate within academic literature. These discussions focus on the concept of physical and mental decline as being a demarcation of the difference between the two fields (Grenier, 2012:170).

"The Fourth Age is constituted in and by Third Age normality; it is the troubling excess of the positive and active Third Age. It cannot be assimilated to the discourse of positive ageing and solutions of the Third Age" (West & Glynos, 2015:7).

The Fourth Age is positioned as a social imaginary rather than a stage in the life course because it represents a “collectively imagined terminal destination in life” (Higgs & Gilleard, 2015:14). Gilleard and Higgs (2013b:369) draw on Castoriadis’s (1987) view of the social imaginary as that which forms part of a society’s view of itself “which is at the same time a view of the world which is part of its truth or its reflected reality without being reducible to it.” This idea of the social imaginary has similarities to Durkheim’s concept of the ‘collective representations’ or Williams’ (1997) ‘structure of feelings’: the way a society conceives of or imagines itself (Gilleard & Higgs, 2013b:369). In terms of the Fourth Age, Gilleard and Higgs (2013b:374) suggest that it is a re-emergence of a pre-modern distinction between ‘senectus’ (old age) and ‘senium’ (senility) which were replaced by the social category of old. They argue that its re-emergence can be linked to three phenomena: the medicalization of later life, the densification of disability in long term care, and the emergence of the agentic cultures of the Third Age (Gilleard & Higgs, 2013b:374). The Fourth Age is also perceived as something that happens to other people; Bataille (1993/1999 c/f Gilleard & Higgs 2013b:375) suggested that it creates an ‘abject class’ whose defining feature is not what social or economic goods they do or do not possess, but rather what kind of stranger we fear ourselves becoming.

The Fourth Age is characterised by frailty. ‘Frailty’ is used to some extent to classify and determine eligibility in public health and social care services and is a construct that has come to symbolise later life (Gilleard & Higgs, 2011b; Grenier & Phillipson, 2013). While it is widely considered that the Fourth Age is closely linked to frailty, there is currently no consensus on the definition of the concept of frailty (Rodriguez-Manas et al, 2013). The World Health Organisation defines a frail older person as ‘an older person in need of a substantial level of care and support’ (Nicholson et al, 2012:2). The biomedical definition emphasises a state of vulnerability which increases the risk of adverse outcomes such as falls, delirium and fluctuating disability (Clegg et al, 2013:752). Grenier (2006) explores the emotional impact of being categorised as frail in her paper examining the difference between ‘feeling’ and ‘being’ frail. She argues that “movement into this period can be critically read as a transition that occurs on a physical, socio-cultural, interpersonal and emotional level” (Grenier, 2012:174). Grenier (2006) suggests that it is possible to experience frailty as a temporary condition linked to emotions such as grief. Bortz (2007) makes the point that immobility and malnutrition are prime causes of frailty and this also raises the possibility that frailty can be reversed in some circumstances. Bortz (2007) points out that old people can be sturdy when fit and fed and young people can be frail when immobilized and malnourished. This understanding

disassociates frailty from age and raises problems with the focus of frailty as a point of no return within Fourth Age theorising.

The above discussion has shown that a sociology of old age is increasingly difficult to demarcate (Gilleard & Higgs 2013b:375). The vast range of experiences of later life is illustrated in the differences between the cultural field of the Third Age with its emphasis on choice, autonomy and self-expression and that of the Fourth Age with its fear of frailty and abjection. In order to explore the experiences of later life and the impact of the social construction of ageing, it has been argued that research should begin with the ageing body (Katz, 2010:357).

The Ageing Body

In recent years, social gerontology has discussed the ways in which the lives and experiences of older people are not so much determined by biology as by social processes and divisions, particularly those of class and gender (Twigg, 2006:41). From this perspective, attempts to include detailed discussions of the body can appear to be a retrograde step as they may return the focus to bodily decline and loss of function (Twigg, 2006:41). However, the ageing body cannot be denied and in any discussion of ageing and care the body is the central issue, the site where care is performed and received. The concept of embodiment highlights the significance of the body as central to human experience (Howson, 2013:17). The theoretical perspective that underpins this thesis draws on the work of Michel Foucault for whom the body is the ultimate site of the exercise of political and ideological control (Twigg, 2000:11). Foucault did not directly address issues of the body in old age but Katz (1996) and others have developed his insights in relation to the development of gerontological knowledge to show how old people have been constituted as the subjects of power and knowledge through the disciplines of gerontology and geriatrics (Twigg, 2000:15).

Post-structuralists argue that linguistic categories determine our bodily knowledge and experience (Shilling, 2012:75). For Foucault, the body itself has no pre-discursive existence, there is no natural body underlying social process; rather it is created through the processes of discourse themselves and can only be studied by means of the history of the discourses that have formed it (Twigg, 2000:11). Biggs and Powell (2001:3) suggest that "insofar as there is a history of ageing, there is a history of efforts to control, supervise and self-regulate the ageing body." Traditionally, the dominant discourses of ageing have constructed age as physical decline. These discourses have shifted from exploring ageing as a disease towards examining

the mechanisms or root causes of ageing itself, where attention is focused on ways to prevent or cure these problems (Grenier, 2012:88)

This continued focus on ageing as a problem and something to be avoided impacts on individuals' experiences of the ageing body. An example of this connection is the concept of the body as a mask which hides the inner self and is found in discussions of race and gender but most prominently in age (Shilling, 2012:226). The theory of the 'mask of age' was developed by Featherstone and Hepworth (1991) and raised two issues for the study of ageing. Firstly, there is a gap between the physical presentation of ageing, the way that others perceive the ageing body and the subjective experience of the ageing individual (Faircloth, 2003:17). Secondly, the vocabulary of ageing limits the potential for expressing personal feelings that are different from the prevailing stereotypes (Faircloth, 2003:17). The mask is seen as either a straightjacket or a performance depending on the degree of awareness, control and choice that individuals feel that they exercise over their appearance (Shilling, 2012:226).

The connection between our sense of self and how others see us is linked to Cooley's (1902) theory of the looking-glass self which refers to a person's beliefs about how he or she is perceived by significant others and that these beliefs determine how the individual constructs their self-image, as though the beliefs of others are reflected in themselves (Cook and Douglas, 1998:299). Despite this reliance on others for awareness of our self-image, it is also true that this can never completely define us since different people will have different views of us and, indeed, we can take action to redefine ourselves (Burkitt, 2014:113). This concept is particularly important in exploring experiences of older people who have to deal with the difficulties of others' perceptions of the ageing body. Throughout the life course there are circumstances and events that jeopardize the dependability of our bodies and threaten the flow of social encounters (Bendelow & Williams, 1997:59). Bodily betrayals such as belching, farting, dribbling and incontinence have the potential to undermine the integrity of social encounters by damaging our self-image and social identity (Howson, 2013:27). These increases in bodily betrayals in later life are closely linked to the fear of appearing abject.

Abjection is defined as a condition that is 'extremely unpleasant and degrading' or a person or their behaviour that is completely without pride or dignity (Oxford Dictionary). Higgs and Gilleard (2015:80) suggest that abjection within the Fourth Age can refer to both people and processes:

“The analysis of abjection requires consideration of not only what is disgusting but also what material social processes render a person or persons abject, by what kinds of abject things and what principles of social organisation govern its associations and attributions.”

Higgs and Gilleard (2015) argue that the concept of the abject cannot be separated from that of disgust, objects or matter that evoke disgust form a major category of abject things. Bodily substances are perceived largely as dirt and have designated places that are generally hidden from public view because when such products leave the body they are considered to be on the wrong side of the boundary, they become ‘matter-out-of-place’ (Douglas, 1966). Dirt in this framework is anything that is defined as matter-out-of-place, anything that has crossed a body boundary (usually an orifice) and is, therefore, in the wrong place (Howson, 2013:96). However, it can be argued that in identifying what is abject it is not enough to list body products such as urine and faeces one must also consider their relationship to the embodied person who has excreted them. In later life, it is not bodily fluids alone that constitute matter out of place:

“food spilled down one’s clothes or in one’s lap. Toenails thickened, stained and curled deep into the flesh, hair matted and greasy, skin covered in sores, hairs sprouting from the nose, the ears or the chin, growths on the face, swollen and sagging flesh round the ankles, the abject objects of old age extend beyond the products of the body, serving as signs of weakness” (Higgs & Gilleard, 2015:81).

Thus *people themselves* can be constructed as abject and it is descriptions such as these that make the Fourth Age so difficult to accept and discuss. Academic debates in sociology seek to avoid derogatory stereotypes yet this appears to be a portrayal of the worst aspects of ageing. Indeed it is, but it can be argued that we need to articulate that this is what happens to some older people and it is these concerns that make us fearful of facing ‘real’ old age.

The construction of the ageing body is gendered, with older women seen more negatively than older men (Higgs & Gilleard 2015:83). Women undertake practices to avoid the appearance of age, for example they dye grey hair and pluck facial hair, but when increased agedness leads to loss of mobility or visual acuity and these practices stop then age becomes more visible (Higgs & Gilleard, 2015:83). Women become “little old ladies”: “small in stature, fragile, weak” (Grenier & Hanley, 2007:213). Whilst this construct may seem harmless, the accompanying assumptions of being mild mannered, polite, passive, weak and powerless provide a guide for the ways that institutions, social policies, and organizational practices shape the gendered experiences of older women (Grenier and Hanley, 2007:213). Calasanti (2003:18) points out that it becomes difficult for older men to continue to perform the

hegemonic masculine characteristics of physical strength, professional success and self-control over certain emotions such as grief or shame. She cites Thompson (1994:15): "Older men are portrayed as obsolete currency in a culture that cherishes power." On the other hand, Twigg (2004:62) makes the point that male power resides in money, status and authority and early signs of ageing such as grey hair are seen as signs of maturity and authority. This research seeks to determine how older people negotiate dominant discourses of bodily decline and ways to age 'well'.

The above discussions indicate that ageing is socially constructed and is not bound by chronological or physical changes, instead individual needs, circumstances and situations need to be taken into account when determining whether they have reached 'real' old age. The following section explores the ways in which policy makers have constructed later life and how their approach impacts on the provision of services for those in need of additional support.

Personalisation of Public Services

This section of the literature review examines Foucault's concepts of governmentality and 'biopower' before moving on to the personalisation of public services so that the structural forces that impact on older people's experiences can be considered. Lemke (2001:191) provides an outline of the "birth of biopolitics" which explains Foucault's understandings of governmental power. For Foucault, government refers to a continuum which extends from formal government through to forms of self-regulation, or 'technologies of the self' (Lemke, 2001:201). Foucault defines government as 'conduct' or more precisely as 'the conduct of conduct', a term which ranges from 'governing others' to 'governing the self' (Lemke, 2001:191). Foucault endeavours to show how the modern sovereign state and the modern autonomous individual are connected and how this relationship has changed under the influence of neoliberal political power (Lemke, 2001:200). Foucault sees this as involving two aspects. First, the re-definition of the relation between the state and the economy; for neoliberals, the state does not define and monitor market freedom, the market is itself the organizing and regulative principle underlying the state. Second, the social domain becomes part of the economic domain so that cost-benefit calculations and market criteria can be applied to decision making processes within the family, married life, professional life and so on (Lemke, 2001:200).

The way in which neoliberal processes have come to shape contemporary ageing is explored by Townsend's (1981) structured dependency theory. Townsend (1981:23) argues that the concepts of retirement and pensionable status, institutional residence and rather passive

forms of community care have been developed in both capitalist and state socialist countries in ways which have created and reinforced the social dependency of older people. Such 'structured' dependency is a consequence of the management of modern economies and the distribution of power and status in such economies. Biggs and Powell (2001:12) argue that the theory of structured dependency and the institutionalisation of care in later life provide a position against which one could take an 'identity stance' making old age widely visible and clearing the ground for resistance and the building of alternatives. However, it has been argued that despite this optimism for a new type of civil rights movement the reality is that the alternative view of older people has been limited to ideas of civic engagement (Minkler & Holstein, 2003). Civic engagement itself has been limited to the activity of volunteering while other enterprises such as voting, community activism and caregiving are not valued and are often ignored (Minkler & Holstein, 2003:201). This emphasis on civic engagement solely as volunteerism may devalue older adults for whom such engagement is not possible or is not chosen (Minkler & Holstein, 2008:203). This view of civic engagement is closely linked to the neoliberal view of ageing that extols individual freedom, moral autonomy and choice as the master narrative in how one 'ought' to grow old (Minkler & Holstein, 2008:201). This emphasis on individual freedom and individual responsibility is reflected in the increased association of ageing and risk.

In their analysis of ageing and social welfare, Biggs and Powell (2001:13) suggest that as policy discussions became increasingly associated with risk, there was a corresponding privatisation of that risk and a withdrawal of supports previously assumed to be stable and enduring. Risk in this sense means the probability of physical harm and Beck (1992) extends this definition to assert that this harm is created in social systems that are meant to manage and control the risky activity, and that the size of the physical risk is directly related to the quality of social relations and processes. The increased focus on risk within social policy coincided with a growing reliance on complex systems of managerialism with older people as "consumers" of services. This view of service users as consumers was linked to the idea that people need liberating from the power of the state and this could be done by expanding the reach of choice and voice of the individual (Clarke, 2005:449). Expansion in choice was meant to lead to empowerment of the individual but it also led to an increase in individual responsibility as people were expected to make good choices that would promote their own health and well-being (Clarke, 2005:451). One of the main vehicles for the increase in choice in social care was the introduction of the personalisation agenda which originated in the disability movement

but was particularly relevant for older users of care services because of the neoliberal emphasis on individual responsibility rather than community care (Needham, 2011).

Personalisation emerged as a formal policy commitment in the *Putting People First* concordat (HM Gov 2007).

“[T]here is no ‘true’ meaning of personalisation any more than there is a true meaning of empowerment or participation or choice. Rather, these are contested concepts, terrains of political struggle and debate on which different social forces seek to impose their preferred meaning.” (Ferguson, 2012:57).

Whilst personalisation is a much debated term it is generally agreed to be about independence, choice and control (Needham & Glasby, 2014). Beresford (2008:10) makes the point that one of the ironies of personalisation is that “while its mantra has been ‘involving service users’ and increasing service user ‘choice and control’, service users and their organisations generally feel they have had little say in shaping or development” (Beresford, 2008:10).

The original aim of personalisation was to offer service users choices regarding specific aspects of their care, allowing them to select elements that most closely met their personal preferences (Needham, 2011:54). One of the central means by which policy has attempted to give service users control over service provision has been through the extension of the choices available to them. Extending choice in public services appears a simple common-sense approach to public reform that can be applied to different services (Greener & Powell, 2009:63). However, the goals that the choice agenda is attempting to achieve, and the opportunities of choice for service users, vary across different services and it can be argued that this has led to “thoughtless attempts at transfer between policy areas” (Greener and Powell, 2009:79). In this thesis, it is the concept of choice in social care, and older people’s experiences of such choices (as well as that of their families and significant others), that are being explored, but first, the overarching narrative of personalisation and how this contributes to policy discourses of care is discussed.

Personalisation has been framed as a positive move towards empowering the individual, frames are not policy ideas but rather ways in which political actors ‘sell’ policy choices to the public (Béland, 2005:11). By framing personalisation as beneficial to the individual arguments that there is a risk that it will lead to enforced individualism and isolation by replacing welfare state provision are difficult to sustain (Lloyd, 2014:59). The provision of community services such as day centres are considered part of the ‘one size fits all’ approach of the pre-

personalisation agenda and it has been claimed that the closure of these centres would allow funding to be available for alternative, and more efficient, forms of care (Needham, 2013:94-97). This reduction in the range of community services available has been matched with a reduction in the number of service users who are eligible for support which can either be seen as successful management of scarce resources or a failure to meet the needs of individuals (Lloyd, 2014:58). It is noted that there is a problem in promoting individualised forms of service provision for older people when *en masse* they are regarded as an economic problem for both service providers and policy makers (Lloyd, 2014:58). It could also be argued that where care is concerned with the well-being of others it can be viewed as relational whereas individualisation is commonly portrayed as the opposite, as “the withering of social bonds” (Fine, 2013:423).

Perhaps to avoid the association of individualisation with a preoccupation with the self or the narcissistic withdrawal from social connections, policy discourse focuses on the ‘personalisation’ of services (Glasby & Needham, 2014:187). The term personalisation has been described as sounding inherently positive and something that is difficult to argue against (Glasby & Needham, 2014:187). Those in favour of personalisation argue that it is appropriate to offer everyone personalised services as the aim is to provide a service based on an individual’s needs and no-one has a greater understanding of those needs than the individual themselves (Needham, 2011:52). However, it could be argued that although the circumstances of older people are common within their age group they don’t ‘know’ how to manage the changes they experience, particularly in the context of the crisis and shock that accompany the loss of mobility or bereavement (Lloyd, 2014:62). It has also been found that older people are less likely to take up the option of a personal budget than younger people (Glendinning, 2008). It has been suggested that the reasons for this are not only within the individual but also within the social care system with low staff awareness of, and lack of confidence in handling, the personal budgets option (Ellis, 2007:405). However, this criticism has been disputed and it is argued that the difficulties that stem from the ambiguity and indeterminacy of the policy may play a bigger role in explaining partial implementation than deliberate subversion by frontline staff (Needham & Glasby, 2014:22). Lloyd (2014:63) suggests that the focus on personal budgets is a distraction from the wider concerns regarding care for older people whilst West (2013) argues that it is a ‘fantasy’ that conceals the terminal erosion of state care and welfare more generally.

The focus on personal budgets reflects a general concern regarding dependency; however, as discussed previously, the discourse on dependency has been replaced by a discourse on risk. There are different aspects to risk: the risks that accompany old age such as the risk of giving in to an ageing body, the risk of being too poor to maintain a consumer lifestyle, the risk of being excluded from participation through incapacity that has been externally assessed, the risk of control being taken out of one's hands, and so on (Biggs & Powell, 2001:16). A review of research, undertaken by Mitchell et al. (2012:21), found that many social care professionals feared the consequences of enabling people to take risks, expressing concerns about litigation and worries about the impact on organisations' reputations. Some argue that the care professional's approach to risk should comprise a 'risk-benefit' approach which balances the importance of wellbeing and autonomy against the need for protection from physical harm. For example, the risk of a person with dementia getting lost when going out unaccompanied is balanced against the benefits of exercise, social contact and the reduction in boredom and frustration at staying inside (Manthorpe, 2014:46). The difficulty in determining a solution to the issue of risk is one of the continuing challenges faced by the personalisation agenda.

It is argued that personalisation has not achieved its original aims and Needham and Glasby (2014:21) suggest that there are at least three possible reasons for this: firstly, personalisation is seen by some as a 'Trojan horse' for neoliberalism with a policy agenda to reduce state welfare services; secondly, it is seen as a well-meaning policy derailed by budget cuts since 2010; and finally some argue that it has simply not yet had time to establish itself as a mainstream approach to adult social care services. Duffy (2014:178) points out that in 2010 the new coalition government introduced the most sweeping cuts to public services since the creation of the welfare state. Some have argued that pensions and other benefits should be cut as the solution to the 'burden' of dependency (Walker, 2012:814). Indeed, the resource allocations systems which were designed to empower people have instead been used to cut budgets and local authorities (Duffy, 2014:178). Duffy (2014:178) refers to this as 'zombie' personalisation, a situation in which the language and structures of self-directed support are used but the "underlying spirit is hostile to citizenship".

The reduction in benefits has led to a reduction in the numbers of older people who are eligible for state provided support. 'A Vision for Adult Social Care' (Department of Health 2010:8) emphasizes that whether people receive direct payments or fund their own care and support they should have access to services that meet their needs. Hudson and Henwood (2009:4) identify three types of self-funders: those who are part-funded by the council but

paying the balance themselves; those who would be eligible for council funding but have not applied for an assessment; and those who are paying for and arranging their own care and support, which can range from a little bit of help about the house to permanent residential or nursing home care (Hudson & Henwood, 2009:4).

Currently in England those with savings of £23,250 are required to meet their own care costs and it is estimated that 45% of residential home places and 48% of nursing home places are self-funded (Henwood, 2014:76). Despite the large numbers of self-funders, setting aside money for future care needs is something that is not included by many people planning their finances for later life (Price et al., 2012:390). Although the Care Act 2014 introduces a limit on individual financial responsibility of £72,000 this has not yet been implemented and it is unclear whether, if and when it is put into practice, it will have any impact on people's inclination to plan for care in later life (Department of Health, 2015a). The increase in self-funders together with the increase in choice through internal or quasi-markets has led to an expansion of the view of the service user as a consumer, with access to information and control of resources, and the power of exit from unsatisfactory services (Fotaki, 2010:13).

This section has explored how changes in governmentality have moved from ideas of collective responsibility towards a greater emphasis on individual choice and personal responsibility. The following section explores the debates surrounding research into care.

Care

There is no 'truth' about care or any objective universal definition. Good care is culturally specific and culturally defined (Phillips, 2007:18). Barnes (2012:4) points out that "[w]e assess others according to their capacity to care, to assess someone as 'care less' is a judgement that they are deficient in some way." The general need for care arises out of the fact that not all humans, animals or objects in the world are able to take care of themselves, we need to care for each other and our environment (Tronto, 1993:136). Care is feminized and undervalued in market terms which leads to care policies that rely on women providing much of the care in the paid care sector as well as providing their labour for free in the private sphere (Rummary & Fine, 2012:326). The need for care is seen as a weakness in a society that values public accomplishment, rationality and autonomy and care is seen as the opposite of these qualities as it relates to privacy, emotion and the needy (Tronto, 1993:117). This section sets out the ways that different authors approach the exploration and subsequent understandings of care.

Bowlby et al. (2010:7) offer the framework of 'caringscapes' for investigating informal care at the individual level; suggesting travel offers a notion of travelling through a terrain, a journey of care, so bring into focus the dimensions of time and space. Care needs and relationships evolve and develop over time rather than remaining static (Bowlby et al., 2010:65). The care relationship may be an enduring personal relationship but may also be an occupational or professional relationship that is limited in time and focused primarily on mental and physical well-being (Rummery & Fine, 2012:322). When examining the physical tasks of care, Twigg (1999) notes the way in which the body is arranged according to gradations of privacy. Different parts of the body may be touched by different people depending on the closeness of the relationship, upper arms and back are relatively neutral and may be touched by most people but knees and thighs are more personal areas (Twigg, 1999:392). As well as privacy, touch is also related to power and status and generally it is the more powerful touching and those with less power being touched (Twigg, 1999:392). The changing care needs of individuals may mean that whilst care tasks may initially be undertaken within a personal relationship, this may change over time and become the province of a professional relationship.

Distance is an important factor since contact and care are intertwined, particularly when personal hands-on care is required (Phillips, 2007:112). As geographical dispersion has become a feature of family life, caring for older relatives becomes problematic (Phillips, 2007:114). A 'caringscape' perspective questions the conflation of female biology (such as pregnancy or childbirth) with feminized tasks (such as housework or childcare), since this conflation assumes that women will 'naturally' undertake caring roles. This challenges the power imbalances between those who can choose to care, usually fathers and other men, and those considered 'natural' or more socially appropriate carers, usually wives, mothers and women in general (Bowlby et al., 2010:6). Bowlby et al. (2010:46) point out that we might be motivated to perform caring tasks because we feel we should do so or because we fear the social and emotional consequences of not doing so.

Care may be viewed as a continuum that ranges from informal care delivered within the home-space, through a mixture of informal and formal care delivered at home and finally to care delivered within institutional settings (Milligan, 2003:467). This perspective argues that the distinction between care in formal and informal sites has become increasingly blurred. Fink (2004:149) suggests that care '... straddles and unsettles the boundaries between paid and unpaid employment work and home, rationality and emotion, masculine and feminine.'

The blurring of boundaries between different aspects of care is linked to the need for flexibility in care practices. “[T]o care is to tinker;” to test, touch, adapt, adjust, pay attention to details and change them and continue to do this until a suitable arrangement is reached (Winance, 2010:111). The shifting nature of care contributes to the difficulty in determining one clear definition of ‘good’ care.

One of the aims of care policy in the UK is to keep chronically ill or disabled living at home independently and with dignity for as long as possible (HM Gov: Caring for our Future 2012). The meaning of home is an increasingly important theme in the discussion of identity, control, privacy, security, safety, independence, individuality and autonomy (Phillips, 2007:107). The home provides a spatial distinction between the private world of the individual and the public world outside (Twigg, 1999:383). One of the most disliked aspects of living in residential homes is reported to be the perceived lack of privacy (Twigg, 1999:386). It is argued that staying in their own home allows older people an element of control over their privacy, reducing the degree to which they may feel depersonalised (Twigg, 1999:387). For older people the objects within their home can provide links with the past: who they are and have been can be expressed in their surroundings and in the way that they display their possessions (Twigg, 1999:384).

Despite the links between home, identity and privacy it could be argued that home may not always be the ideal place for older people to continue to live as they become increasingly frail. Some homes are unsuitable in their design, with difficult to access bathrooms and lack of heating; people can be effectively imprisoned in their home through impaired mobility as well as through poverty and locality (Phillips, 2007:109). With the increasing emphasis on the provision of formal care in the home it has been argued that the home as a private space may be contested (Phillips, 2007:109). While there is little doubt that care given within the home locates the balance of power in the caring relationship more firmly in the hands of the care recipient and informal care giver, this is contingent on the extent of need for external or professional care support (Milligan, 2003). Where needs are greatest, the power balance within the home-space will shift in favour of care professionals (Milligan, 2003:462). For carers of the increasingly frail, this blurring of public and private space can mark a change in the meaning and experience of home as the need for care increases the home becomes less private. The power to exclude can be over-ridden by the need for formal care support creating a change in the relationship normally exhibited within private space (Milligan, 2003:462). Domestic space begins to take on characteristics of non-place as it becomes a site

of transience and movement: the home-space becomes a place of work, living rooms taking on features of the hospital ward as health professionals and care- workers move in and out, governed by time constraints (Milligan, 2003:462).

Having explored the dimensions of time and space in relation to the physical tasks of care, we turn now to the emotional facets of care. These emotional aspects are relevant to both informal and formal care givers as well as care recipients. Care recipients may find it emotionally difficult to relinquish their independence and be touched by people that they would not normally be physically close to. Care givers must also manage the emotions that their tasks evoke and this may be discussed in terms of emotional labour. The concept of emotional labour is presented in the seminal work by Hochschild (1983). Hochschild (1983:9) developed the idea of emotional labour through her study of flight attendants who were required to co-ordinate their feelings so that their work appeared effortless, she found that displaying the effort that was required to do the job was regarded as doing the job badly. The term emotional labour describes the way the flight attendants had to manage their feelings to ensure that passengers had a pleasant flight. They did this by 'surface acting', disguising what they felt and pretending to feel what they did not. For example a flight attendant would disguise feelings of fatigue and pretend to be excited about the upcoming flight (Hochschild, 1983:33). For some care workers, their emotional labour may be in the form of this surface acting or alternatively, 'deep acting' whereby they either call upon a feeling directly or use their imagination to recall a feeling and invoke it (Hochschild 1983:39). Emotional labour, as with care work generally, is considered to be gendered and women are required to maintain an overtly feminine and heterosexual appearance, whilst men who seek to engage in care work are often cast as effeminate (Pilcher 2007).

The emotional element of care is an important aspect of the experience of those who receive care and yet emotions are difficult to define and articulate. Wetherell (2012:2) describes how affective studies explore emotional states and the 'distinctive disruptions' that they cause in the body and mind. Whilst Burkitt (2014) concurs with Wetherell's (2012) view of affect as occurring in both the body and mind, he also places a greater emphasis on the connections between emotions and social relations. Burkitt (2014:7) uses the term emotion to denote a 'strong feeling deriving from one's circumstances, mood or relationships with others.' The importance of relationships is appropriate for this research which seeks to ensure that the exploration of the experience of older people takes into account the social networks in which

their lives are embedded. The understanding of emotions is important since 'good' care aims to provide the care recipient with a sense of well-being.

Barnes et al. (2013) suggest that being 'well enough' in old age requires learning about how to live as an older person, particularly in the face of change and different types of loss: loss of friends and family, of health and physical capacity, of roles and sometimes of identity. This adjustment to later life links to the theory of selective optimisation (Baltes and Baltes, 1990) which describes the process by which people concentrate on particular skill areas to compensate for losses in other areas. Developing strategies to keep well in old age can involve both emotional and organizational labour and can be hard work – being 'well enough' is often an appropriate ambition (Barnes, Taylor & Ward, 2013:478). Being well enough may still involve an element of well-being regardless of health and ability. Galvin and Todres (2013:18) suggest that a humanising perspective on care views well-being as a positive quality that makes life worthwhile rather than simply an absence of illness where the body is viewed as an object to fix. This perspective is reflected in the 'logic of care', where care becomes 'something that people shape, invent and adapt, time and again, in everyday practices' (Mol, 2008:5). The idea of people working together to achieve good care is explored further in the framework of a feminist ethic of care that is discussed in the following section.

A Feminist Ethic of Care

The feminist ethic of care is a moral theory developed by Tronto (1993). It stems from the seminal work of Carol Gilligan's "In a Different Voice: Psychological Theory and Women's Development" which argues for an 'ethic of care' rather than an 'ethic of rights'. Tronto (1993) identifies three major distinctions between these two ethics: first, the ethic of care is based on relationships and responsibilities, while the ethic of rights is based on rights and rules; second, the former emerges from concrete circumstances, rather than abstract situations and third, the ethic of care depends on activity while the ethic of rights depends on principles (Shakespeare, 2000:73).

Tronto (1993) seeks to redraw the moral boundaries between public and private life. She is critical of Gilligan's conception of the ethic of care as being almost entirely in terms of personal relationships, ignoring the possibility of connections with larger units such as extended family or community (Tronto, 1993:87). Tronto (1993:190) asserts that the division of public and private life is not a case of separate but equal spheres; the public is argued to be more important than the private so the relegation of caring to private life suggests that it is beneath public concern. Tronto's (1993:180) work explores the possibility of redrawing these

moral boundaries by applying her ethic of care not only to the private sphere but to all of social life:

“Care is not a parochial concern of women, a type of secondary moral question or the work of the least well off in society. Care is a central concern of human life. It is time that we began to change our political and social institutions to reflect this.”

In developing her detailed ethic of care, Tronto (1993) seeks to make explicit the moral aspects of care and to emphasise the relational elements, that we are related not only to other humans but to the world around us, the objects we encounter in our daily lives. Tronto and Fisher (1993) offer a definition of their understanding of care:

“On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex and life-sustaining web.” (Tronto, 1993:103)

This definition makes it clear that care is not only about people but also about the care of objects and can be a single activity or a process. Tronto identifies four phases of caring: first, ‘caring about’ which involves the recognition that care is necessary; second, taking ‘care of’ where someone assumes responsibility for the identified need; third, care-giving; and finally, care-receiving, the idea that the subject of care will respond to the care it receives and will be in a better state or situation after receiving the care (Tronto, 1993:106-107).

Good care is a practice rather than a principle or an emotion, and calling it a practice implies both thought and action and that the thought and action are inter-related and directed toward an end (Tronto, 1993:108). Tronto (1993:127) outlines four elements that link to the phases of care and comprise the ethic of care: attentiveness, responsibility, competence and responsiveness of the care receiver. In order to address the needs of others, we need to be aware of what those needs are. If we are not attentive to the needs of others we cannot address those needs and, within the ethic of care, not responding to another’s needs would be a form of moral failing.

The concept of responsibility is both central to and problematic for an ethic of care and Tronto (1993) suggests that it carries a different connotation to ‘obligation’: responsibility is not about what we owe or what we are obliged to do for others. Tronto (1993:131) argues that the notion of responsibility offers a more flexible perspective for understanding what people should do for each other. Taking responsibility for care but then failing to provide good care means the need for care is not met (Tronto, 1993:133). As well as consideration of the

responsibility of care givers, the ethic of care makes the point that there should be a balance between the needs of care givers and care receivers (Tronto, 1993:134). Responsiveness of the care receiver to the care giver is essential; care cannot be given if the care receiver will not acknowledge that the need exists. To use the ethic of care requires a careful consideration of the situation in which care is taking place as well as the needs and competencies of all the individuals involved (Tronto, 1993:136). Tronto (1993:163) also asserts that dependency at some moments or in some aspects of life need not lead to dependency in all parts of life suggests a lack of ability in one domain does not preclude ability in other areas.

Shakespeare (2000:73) offers a critique of the feminist ethic of care from a disability studies perspective, asserting that there is a fundamental need to apply the ethic of rights to the social relationship of care. He argues that because disabled people's limitations are not qualitatively different from others they should be able to assert their rights in the same way that others do (Shakespeare, 2000:77). It follows that personal assistance is seen as a right rather than being dependent on the kindness of others (Shakespeare, 2000:77). Morris (2013:2) is critical of this view and suggests that the social model of disability is an important element to understanding the debates surrounding dependency. She argues that separating out 'impairment' (that is, the functional limitations of our bodies and minds) from 'disability' (that is, the disabling barriers of unequal access and negative attitudes) is essential to understanding the experience of disability. In many situations, disabled people require resources be made available to allow them equal access to their human and civil rights. For example, disabled children will not have equal access to education unless they have an entitlement to changes in the physical environment of the school (Morris, 2013:13). Without entitlement to the action and resources needed to tackle disabling barriers they are not able to exercise their human rights. This means that their limitations are qualitatively different to those of non-disabled people (Morris 2013:12). Thus, Morris (2013:15) argues that an ethic of care should start from the position that everyone has the same human rights, but also recognise the additional requirements that some people have in order to access those human rights.

Shakespeare (2000:73) asserts that users of care services may feel taken over, spoken for, undermined, disempowered or even neglected and abused by carers. The ethic of care argues that emotion is inseparable from our decisions and good care requires empathy and emotion, although we need also to examine carefully the efficacy of the care we give (Bowlby et al., 2010:46). It is also the case that care can involve the manipulation of emotion, and

withholding or giving love and affection can be used as a means to exert control by the carer over the cared-for (Twigg, 2000). Sevenhuijsen (1998) makes the point that there is another side to caring:

“Even if care is to a certain extent generated by dependency and attentiveness, the concrete motives in social practices of care cannot always be derived from the urge to protect dependent people from vulnerability. Caring for others can also stem from less noble motives, such as the urge to meddle or to control others.” (Sevenhuijsen, 1998:20)

The ethic of care emphasizes interdependence yet for those in need of care the discussion of independence versus dependence is of particular importance. Feder Kittay and Feder (2002:4) suggest that claims of independence arise from “invisible or unacknowledged dependencies on others, or on economic or political institutions and on social understandings of what constitutes dependence and independence” (Feder Kittay & Feder, 2002:4). Such claims of independence are understandable when images of dependence are mostly negative (Fine & Glendinning, 2005:607). Fine and Glendinning (2005:615) suggest that independence is perhaps best understood not as non-dependence but as relational autonomy. Relational autonomy is an approach to understanding people’s actions and identities by considering the roles of social norms and cultural practices at play in shaping experiences (Mackenzie & Stoljar, 2000:20). Interdependence is about exchanges between dependent actors over time. Rather than there being an expectation of direct and immediate reciprocation between care giver and care recipient there may be a delayed reciprocation or even transferred responsibility where if necessary others within a community respond to the need (Fine & Glendinning, 2005:612).

Lloyd (2010) suggests that a focus on the need for care in circumstances of frailty and ill-health in old age is a valuable way of understanding the dependencies that human beings share. The ethic of care is a framework for understanding the giving and the receiving of care that has the potential to influence not only ways that care is provided but also the ways in which dependency is perceived to be experienced at this stage of the life course (Lloyd, 2010:196). The feminist ethic of care provides a view of care as interdependence and allows for the consideration of both the care giver and the care recipient. By recognising the role of both parties in the concept of relational autonomy then the binary emphasis of dependence versus independence can be diminished.

Lloyd et al.'s (2012) exploration of identity in the Fourth Age found that participants’ care relationships were about more than the support needed to complete basic tasks, they were

the means by which participants were able to maintain their capacity for autonomous decision making. It was through their current relationships that older people could see a way of continuing to be themselves and to maintain a social life in the context of bodily decline (Lloyd et al., 2012:19). Lloyd et al. (2012) suggest that their findings support the concept of 'relational autonomy' and argue that there was no loss of agency, in the sense of increasing subjection to the will of professionals (Lloyd et al., 2012:17). Relational autonomy holds that it is through engaging in relationships with others that identities are formed (Mackenzie & Stoljar, 2000:21). Changes in identity and the possibility of exercising agency in later life are inextricably linked with changes in intimate and wider social relationships. In old age, this includes increasing relationships with professionals and carers (Lloyd et al., 2012:15).

Nicholson and colleagues (2012:8) found that frail older people who were defined as frail were able to adjust to the accumulated losses in physical, social and psychological domains through interaction with carers. The participants within this study saw their carer visits as someone "keeping an eye on them" as well as the opportunity to have someone to talk to and interact with (Nicholson et al., 2012:6). This study suggests that by adjusting to their surroundings and continuing to enjoy social interaction the participants went against the stereotypical image of frail older adults which focuses on disengagement, vulnerability and a 'lack' of agency (Nicholson et al., 2012:8). Nicholson et al. (2012:1428) argue for a state where identity is continually negotiated and describe the physical and psychological effort of living in a persistent 'betwixt and between' state. Kelly (2008:336) describes liminal states as cultural fields, an in-between place, on the threshold between here and there. The concept of liminality suggests that there is more to old age than the binary view of good health and active lifestyles or decrepitude and dependency and emphasizes that care relations are an important part of adjusting to the changes of later life.

In order to explore how care relations differ from individual action the following section explores the debates surrounding agency and how such understandings can aid or constrain choice.

Linking Choice and Agency

Agency can be defined as the human capacity to exercise choice, to act intentionally and reflexively (Marshall, 2005:67). Marshall (2005:68) argues that there are three constructs that are relevant to the analysis of agentic behaviour: first, the resources within, or, at the command of, the individual, either acquired capacities or other resources such as social capital or fiscal assets; second, that the behaviour of individuals reflects intention; and third that the

social and physical structuring of choices takes into account the wide variation in the personal, social, and economic resources that people can employ (Marshall, 2005:69). These constructs demonstrate that we must look at the resources available to, and capacities of, older people when considering their ability to exercise choice.

When exploring agency, the first question to consider is at what level the analysis should take place. Should agency be explored from the individual's perspective or at a structural level (Marshall & Clarke, 2010). Marshall and Clarke (2010:295) assert that "social actions are enabled and constrained by social structures whilst social structures are constituted by social action". They offer some examples of studies that deal explicitly with the relationship of agency to social structure in ageing and lifecourse research (Marshall & Clarke, 2010:300). One such study shows that macro-level social resources are influential for the successful implementation of micro-level processes of adaptation to illness and disability. Clarke and Black (2005:333) found that adapting to one's physical and cognitive limitations was an important strategy for the maintenance of subjective well-being following a stroke. Economic resources (for example, having the means to purchase a car with leather seats to make it easier to get in and out of) and social supports (such as a spouse's help to develop a system to overcome memory problems) were some of the many structural resources that either facilitated or discouraged these micro-level adaptive strategies. Many micro-level theorists implicitly recognise the importance of these structural constraints and opportunities for adapting to poor health and disability in later life (Marshall & Clarke, 2010:300). This research adopts a micro level of analysis in order to explore the impact of social policy on individual choice.

Older people with impairments may experience more, or more severe, constraints than earlier in the lifecourse. As their level of function decreases, they may be less socially mobile and may rely on care support services or family and significant others (Grenier and Phillipson, 2013:64). Grenier and Phillipson (2013:62) argue that the definition of agency needs to shift toward a more fluid interpretation whereby older people may express themselves through touch or voice, rather than language. Interpretations of agency assume awareness and control on the part of the individual (Grenier and Phillipson, 2013:67). If cognitive competence is an essential element of agency then this would mean that dementia would preclude one from exercising agency and if this is the case then other situations where mobility and/or communication are strained or difficult must also impact on the possibility of agency (Grenier and Phillipson, 2013:67). Scholars writing in relation to disability have criticised the control

and able-bodied assumptions that are embedded in this view of agency (Grenier and Phillipson, 2013:67). In exploring the possibility of alternative expressions of agency, Bourbonnais and Ducharme (2010:1182) examined the meanings of the screams of older people living with dementia. They identified screaming as a language that is unique to the older person but that could be learned. They found that screams expressed dissatisfaction or disapproval about situations or specific care but could also express satisfaction with actions (Bourbonnais & Ducharme, 2010:1177). It also shows that even those who have lost their ability to engage in discourse are still able to exercise power if those around them are attentive to what is being expressed (Bourbonnais & Ducharme, 2010:1182). The importance of the relational nature of agency has been explored by Gubrium and Holstein (1995:558) who suggest a framework that allows people to make use of locally-shared understandings, biographical details and material resources around them and so apply dimensions of ordinary experience in order to convey agency. For example, the use of material resources allows for means of self-representation and may be achieved by an individual referring to a scene outside a window where a weed can be seen growing through concrete and this might be used to illustrate the strength and determination they feel that they require to carry on in difficult circumstances (Gubrium & Holstein, 1995:584).

It is understood that those that exercise agency are emotional, embodied, desiring and creative as well as rational creatures (Mackenzie & Stoljar, 2000:22). In understanding the emotional aspects of agency it is necessary to take into account feelings of empowerment:

“differing modes of emotional being - physical and psychic states which can be either ‘pleasant’ or ‘unpleasant’ - affect, different felt ways of feeling empowered or disempowered: feelings which are very much linked to people’s material and psychosocial conditions of existence throughout their embodied biographies” (Williams, 2000:568).

The consideration of individual contexts is fundamental to understanding how the experience of choice is mediated by emotions and implicated in axes of power. Psychosocial perspectives consider the emotions, fears, anxieties and destructive moments that may be a part of expressions of agency (Hoggett, 2001:38). Hoggett (2001) argues that understandings of agency must be broadened in order to include subjects located within the experiences of powerlessness and psychic injury. He suggests that:

“A robust model of agency must also confront the subject’s refusal of agency or the assertion or forms of agency which are destructive towards self and other, and that it is both possible and necessary to explore such ‘negative capacities’” (Hoggett, 2001:38).

Hoggett's (2001) view challenges the expectations of choice, rational action, and more importantly, the assumption that the agency expressed by individuals is always positive and straightforwardly 'empowering', and makes the point that there is a problem in equating agency as good and the absence of agency as bad (Grenier and Phillipson, 2013:63).

It is recognised that choice is not always the result of reasoned deliberation, that most choices are made on impulse in urgent and contingent encounters requiring on-the-spot decisions as our own and others' needs, expectations, and feelings press in on us (Hoggett, 2001:40). It is in these situations that mechanisms of power can be identified and the process of 'subjectification' takes place that is the historically located, disciplinary process that influences the decisions and actions of individuals (McHoul 1993:3).

The importance of the emotional aspects of agency are echoed by Davenhill (2007:30) who argues that whilst 'person-centred care' is a rational and humane perspective, it breaks down conceptually as it takes the 'un' out of 'unconscious' and leaves itself working at the level of conscious thought alone. In discussions of agency, aspects of the 'unconscious' are explored through a psychosocial lens that seeks to identify the emotional subtext of care decisions. Hoggett (2001:47) proposes that we think of agency and reflexivity as continua and proposes a model as a way of thinking about the different subject positions that we all occupy at times rather than as a typology for characterising particular individuals as non-reflexive or reflexive. This model has two axes with a continuum ranging from the self-as-object to the self-as-agent on the horizontal axis and the reflexive self to the non-reflexive self on the vertical axis. At one end of this continuum, the subject can be seen as a reflexive agent: rather than a passive victim of welfare discourses, gender relations or poor environment, the subject is an active, conscious shaper of his or her history, albeit not in circumstances of his or her choosing. At the other end of this continuum is the non-reflexive subject whose actions are impulsive and whose choices do not always result in a positive outcome, although Hoggett (2001:48) does note that impulsive acts can also be acts of extreme heroism, self-sacrifice and kindness. On the alternative axis, the continuum that ranges from non-agentic to the agentic, the non-reflexive non-agentic individual experiences powerlessness due to marginalisation and domination by others but regards this as their fate. At the other end of the scale, the reflexive subject may be aware of the impact of powerful forces, such as illness or prejudice and yet are unable to do anything about it (Hoggett, 2001:50). It has been suggested viewing agency as such a continuum could reinforce the idea of a gradual slope that moves the older person closer to an unagentic position over time (Grenier and Phillipson, 2013:71). However, non-

rationalist models such as that proposed by Hoggett (2001) are more able to accommodate the contradictions of everyday experiences.

The above discussions provide a rationale for further exploration of the choice in the context of care relationships and relational autonomy. The structural forces that impact on an individual's ability to exercise agency must be considered when exploring choice at an individual. The concept of non-rational, unintentional or harmful agency provides a basis for looking at choice in a way that differs from the language of empowerment and control that is prevalent in policy discourse. In considering the ways in which choices are made in 'real' old age, both conscious and unconscious expressions of needs and wants may need to be interpreted. In order to more fully understand how these needs may be communicated and understood in real world situations the following section explores the process of choice in health care.

The Process of Choice in Health Care

Health care has a longer history of emphasis on choice than the social care sector. This is due largely to the fact that patient involvement in decision making has been associated with greater adherence to treatment (Edwards et al., 2009:38). Decision making models have been developed to understand how patients can actively be involved in their treatment decisions despite the power imbalance that may exist between patients and their physicians.

Mol (2008:9) makes the point that although patients undergoing treatment may be described as receiving it passively, they are in fact active and undertake a lot of their care themselves. In her study of diabetes patients, she describes how people with diabetes inject their own insulin, measure their own blood sugar levels, calibrate their exercise and take care of themselves in other ways as well (Mol 2008:9). These actions are linked to Foucault's technologies of the self and the productive aspect of power, particularly medical power, that works by persuading people to undertake activities and practices, or exercise self-discipline, because they believe them to be in their best interest (Howson, 2013:157). Individuals discipline themselves in this way because of the influence of medical discourses but the power of these discourses is not solely repressive and the relational nature of power allows for resistance (Lorentzen, 2008:53). Whilst society imposes a variety of constraints, individuals have many options as to how they choose to act and there is always the potential for resistance (Lorentzen, 2008:56). This resistance will depend not only on the goals of the individual but also on the goals of those with whom that individual interacts and the success of

attempts to act agentically must take into account other aspects that will impact on social interactions.

The most notable interactions within health care treatment making decisions are those between patients and doctors. Decision-making models have been developed to show the varying degrees of involvement of both the doctor and the patient when making choices about treatments. This section explores these models in order to understand how individuals can be unintentionally excluded from a decision.

Charles, Gafni and Whelan (1997 and 1999) offer a conceptual framework that identifies the different analytic steps in the treatment decision making process: information exchange, deliberation about treatment options and deciding on the treatment to implement. This analysis of the process has led to the development of a model that indicates the level of involvement of patients in decision making as being either paternalistic, shared or informed decision making (Charles et al., 1999:653). These types of decision making are seen as being points along a continuum, where the amount of participation preferred by the patient ranges from the doctor making the decision, through a shared decision, to the patient making the decision alone (Charles et al., 1997:687). In order to understand how the models differentiate between different levels of patient involvement in decisions, the following discussion describes the typical features of each model.

In the paternalistic model, the physician recommends tests and treatments for the patient whilst the patient's involvement is limited to consenting to what the physician thinks best (Charles, Gafni and Whelan, 1997:683). Most agree this is not an appropriate model for current decision making and treatment contexts, although in emergency situations it might be the only feasible option (Charles, Gafni and Whelan, 1997:683). Within the informed decision making model, information exchange is one-way, from physician to patient, and the remaining tasks of deliberation and decision making are the patient's alone (Charles et al. 1997:654). The paternalistic model leaves the patient out of the process and the informed model leaves the physician out of it (Charles et al., 1997:653).

The ideal approach is considered to be the shared decision making model where the physician and the patient work together to arrive at the decision (Charles et al., 1997:683). As well as exchanging information, the physician ensures that the patient has an accurate understanding of the relevant information and that their fears and expectations of possible options are discussed (Elwyn et al., 2000:895). In a shared approach, each person needs to be willing to

engage in the decision making process by expressing treatment preferences (Charles et al., 1999:658). It has been argued that older people's preferences regarding involvement in decision making may differ from that of younger people. Lachman (1986) suggests that this can be related to the belief that people hold regarding their control over their surroundings. The consequences of this understanding were explored by examining whether there was a correlation between patient preferences within decision making and the reasons for the health care encounter (Schneider et al., 2006:296). It was found that patients with minor complaints had a higher preference for involvement than patients with chronic or severe diseases. Older patients generally tended to have lower preferences for involvement (Schneider et al., 2006: 296). Schneider et al. (2006:297) suggest that a general preference for less involvement by patients with chronic diseases supports an argument that some older patients could feel more comfortable with a paternalistic approach to decision making. This is echoed by research into choice in consumer behaviour which suggests that whilst people may prefer to have increased choice, in certain situations they feel better about the outcome of a decision if the decision is made by someone else (Iyengar & Lepper, 2000:1004). A study by Belcher et al. (2006:300) found that some patients felt that if they trusted the doctor they would let him or her make a treatment choice for them but others felt that trusting a physician would make them feel more able to ask questions and so participate more in the decision. Conversely, a lack of trust was seen by some as a reason for not sharing feelings or concerns, thus impeding a person from taking part in a decision (Belcher et al., 2006:300). An additional difficulty within the doctor-patient relationship is the focus by doctors on different aspects of health without adequately appreciating their relation to the whole person (Stange, 2009). This can lead to well-intentioned actions that sometimes have the unintended consequence of making things worse (Stange, 2009).

It has been acknowledged that the focus on the process within the health care encounter ignores events before or beyond that point in time. Tyrell et al. (2006) developed an alternative model that could explore the impact of decisions beyond the health (or social) care encounter. This explored five dimensions: the information made available to the service user; the extent to which a service user considers they are being listened to by the professional; the extent to which they are able to express their opinions about options; the time available to service users to reflect on options before making a choice; and the possibility of being able to change their mind if the decision taken does not suit (Tyrell et al., 2006:482).

Through the application of this model it was found that carers tended to be much more satisfied with the information received from professionals than were service users. With regard to being listened to and allowed to express opinions, some service users with dementia commented that they felt 'unheard' by both professionals and their carers (Tyrell et al., 2006:489). Mol (2008:97) makes the point that when service users complain about health care, they may mention they were not given a choice, but more often they talk about neglect and describe how their particular stories or personal experiences were not attended to.

The dimensions explored above offer a description of the service users' experiences and together with the health care shared decision making model give a greater understanding of the barriers to and facilitators of health care service user involvement in decision making. The treatment decision making outlined here is very different to social care choices as the options are limited by the doctors' judgement on which treatments it is appropriate to offer. However, the models are useful in providing a general understanding of the ways in which the involvement of individuals in decisions can vary. The following section explores research undertaken into the process of choice in social care.

The Process of Choice in Social Care

Despite an ongoing commitment by government to encourage greater collaboration between the NHS and social services, there continues to be differences in the way that the two sectors approach choice (Department of Health, 2015b). Whilst the NHS recognises the power relations that impact on treatment decisions and the subsequent importance of shared decision making, the social care sector continues to emphasise individual choice. Research into the implementation of personalisation in the social care sector has focused on the challenges faced by individual services users during the process of making choices, in particular the provision of appropriate information which is needed before a choice can be made.

It is understood that the process of finding and using information requires effort, time and material resources (Baxter et al., 2008:197). While Schwarz (2004) has argued that the more options that are available the more difficult choice becomes, Hanoch and Rice (2006:43) suggest that there is a difference in decision making at different stages of the life course. They found that, when given the same amount of information as younger people, the older people in their study examined less information before making their decision (Hanoch & Rice, 2006:41). In support of this finding, it has also been shown that when making decisions

regarding health care policies, older people preferred to have fewer options than younger people (Reed et al., 2008:673). As well as the amount of the information that is provided, the source from which it is derived has been found to be important (Baxter et al. 2008:198). In health care situations, the source of information is often easily identifiable: a GP, consultant or specialist nurse. In social care, however, the sources of information are not so obvious. For people whose needs arise from an accident or sudden illness, access to information regarding social care may be facilitated by the care teams involved in managing the crisis. People with a fluctuating or gradual onset of needs generally have to seek information about services themselves (Baxter & Glendinning, 2011).

Baxter, Glendinning and Clarke (2008) undertook a scoping review of projects aiming to improve the accessibility of information about social care services and found that information needs to be in an appropriate format, easy to find, personalised and high-quality. Additionally, the service user must be willing to accept that they need to make a choice. Themessl-Huber et al. (2007:226–228) found that older people were reluctant to activate formal services or carers, even in emergency situations; this was partly because they preferred to wait for a familiar person such as a relative or a GP to provide the care and partly because of fears of losing their independence or appearing frail. This may lead older people to delay their search for information regarding social care services until their need becomes urgent and a decision needs to be made quickly. These fears of losing independence can also lead to older people refusing services altogether and denying that anything is wrong or that external help is needed (Arksey & Glendinning, 2007:18).

For an alternative view on the way in which choices are made, Mol (2008) compares the role of the consumer in choosing a product with the way that care is delivered, contrasting the logic of choice with the logic of care. Mol (2008:20) asserts that introducing market systems to care draws a limit: what is on offer and what is not on offer must be specified and care becomes a delineated product that must have a beginning and an end. In Mol's (2008) logic of care, care is an interactive, open-ended process that may be shaped and re-shaped depending on its results (Mol, 2008:23). For many old people, increasing age brings an increase in health problems and an older person may find their circumstances changing and their needs for care fluctuating so that it may be necessary to make frequent and different choices (Glendinning, 2008:462). Glendinning (2008:465) suggests that, in light of these changes, choice should be 'reconceptualised as a dynamic process in which decisions are constantly reviewed'. It is also recognised although the move to position older people as active agents rather than passive

recipients of care is generally a good thing there will always be some older people who will require support to make decisions (Broome et al., 2012:27). It has been argued that choice and control are only meaningful if they go hand in hand with support: peer support, family support and support from professionals (Glasby & Needham, 2014:189).

The above discussion has shown that, in the context of social care, discussions of the process of choice have focused on the provision of appropriate information. The Social Care Institute of Excellence (2012) provides a rough guide to personalisation and talks about people needing “access to information, advocacy and advice so they can make informed decisions”. However, debates surrounding the personalisation of care are shifting from concerns about individual choice and responsibility towards a greater awareness of the role of trusted and meaningful relationships (Glasby & Needham 2014:190).

Understanding ‘Care’ and ‘Choice’ for Older People

This literature review has provided an overview of the understandings of ‘choice’ and ‘care’ in the context of later life. In ageing research it is acknowledged that later life allows for multiple identities and experiences. While this study focuses on those in need of care it adopts the view that ageing bodies are not simply a problem to be controlled or managed. The construction of old people as abject and frail leads to a fear of, and resistance to, the ageing process which may impact on older people’s willingness to make choices about their care.

Any exploration of the making of choices about care needs to consider what it means to give and receive care. The feminist ethic of care acknowledges that individuals have a need to care for each other and the world around them and to neglect to do so is regarded as a moral failing. The ethic of care emphasises the relational nature of care asserts that there we need others to care about us throughout the lifecourse but dependency in one aspect of our life does not mean dependency in all areas. It is recognised that there is no point at which we do not need to be cared for, or about, but that the level of care needed will vary according to an individual’s ability to care for themselves. Discussions of ageing and care must consider the emotional aspects of the vulnerability that come with losing aspects of independence and studies have provided a more optimistic view of ‘real’ old age by exploring the way that older people maintain their identity through the continuation of close relationships.

The delivery of care in England is impacted by the personalisation of services with an emphasis on individual choice, control and independence. This policy approach influences the community services available to both those eligible for state support and those who self-fund

and has led to a reduction in community services and an increased emphasis on care in the home. This focus on individual choice appears to ignore the fact that older people's lives are embedded in networks of friends and family. The difficulties faced by older people in finding information about services lead to the involvement of friends and family in the process of arranging care, the extent to which older people are actually involved in the final decision warrants exploration. The disparity between the language of choice in the framing of the personalisation of care services and the language of the ethic of care where the emphasis is on care relations and relational autonomy provides the foundation for this research that seeks to disentangle care and choice to gain a greater understanding of older people's preferences.

Insights from healthcare decision-making models suggest that older people's preferences for choice may differ from those of younger people. Older people may indeed prefer that they are not required to make choices about all aspects of their care and would rather that others make certain decisions on their behalf. This raises the question of whether older people's preferences in social care are different from those of people earlier in the life course, such as those in the disability movement who seek control and the opportunity for autonomous decision making. The contrast between the ethic of care and the ethic of rights provides a basis for examining care choices as a relational activity rather than an abstract human right. The concepts of care and choice are influenced by emotional reactions and power relations within social networks. In order to understand how older people experience care in later life, we need to disentangle these concepts and explore how they are each perceived and experienced in different circumstances. The following chapter sets out the research methods that were selected in order to explore the experiences of older people, their families and significant others.

Chapter Three: Research Methods

Introduction

In order to understand the experiences of older people and their care choices, research methods were needed which would allow the participants to frame their experiences in their own way. The methods selected for this research were an initial focus group study and semi-structured interviews that are examined through narrative analysis and informed by a feminist approach. The feminist approach is appropriate first and foremost because I am a woman and a feminist. Within the context of research this provides me with sensitivity towards gender issues but does not mean that I have no interest in the experiences of men. Rather, my research starts from a recognition that gendered relations shape unequal power relations within society, and thus will be implicated in people's care relationships. Feminists insist that it is not possible for researchers to be completely detached from their work: emotional involvement cannot be controlled by mere effort of will and this subjective element in research should be acknowledged, even welcomed (Letherby, 2003:68). In this sense, I consider research to be a two-way process, recognising the impact of my own social world upon the research process, and considering research to be a joint process whereby the researcher and research participant both influence the way the research topic is explored and understood. Feminism is particularly apt for this project as it provides a focus on the experiential and private rather than the abstract and public (Letherby, 2003:42), and it privileges the voices of the researched to articulate their own experiences in shaping ways of knowing.

This chapter sets out the research design, beginning with the research questions and research aims. The research design section includes discussion of a focus group study that was undertaken to guide the development of the later research strategy and is followed by discussion of sampling, ethical issues, a summary of participants and a discussion of the interview experience.

Following this is a section on the selection of the method of analysis, together with a discussion of the importance of representation with regard to transcription and analysis. I chart the ways in which developing a narrative dialogical analysis was considered crucial for privileging my research participants' stories about their own lives. Within dialogical narrative analysis it is common to present stories by grouping them by type, however, it can be argued that this makes it difficult to include unique experiences that do not correspond with the qualities of any particular type. Phronesis, the inclusion of stories that 'call out as needing to

be written about' (Frank 2012:43), is employed within this thesis as this technique allows for the participants' narratives to be presented as both an overall story of common care needs and solutions, as well as distinct experiences portrayed in individual stories. First, the theoretical underpinnings of the research are discussed. The chapter concludes with a discussion of the rationale for presenting the narratives as an evolving story of care.

The following section sets out the research questions that this thesis seeks to answer.

Research Questions and Aims

How do older people, their families and significant others understand care and choice in later life?

How does the policy emphasis on individual choice impact on decisions relating to formal care in later life?

How does the concept of choice relate to the practice of caring? Does examining care activities improve our understanding of care choices in later life?

This research aims to understand how the concepts of care and choice are linked together and to explore whether disentangling these notions provides us with a clearer view of the experience of arranging care for older people.

The experience of arranging care for older people involves not just the older person themselves but their families and significant others and so to fully understand the context in which care choices are made the research aims to explore the experiences of both older people and their families and significant others.

The discourse of choice heavily influences policy on social care and this research seeks to explore the extent to which the emphasis on individual choice is reflected in experiences of giving and receiving care in the context of later life.

Research Direction

In a discussion evaluating the role of care and drugs in dementia care, Moser (2010:278) quotes a professor who she said "exclaimed in a mixture of despair and disillusionment: 'But what shall we do? Count tears?'". Moser (2010:278) suggests that from the perspective of care, counting makes no sense. Similarly, in the context of my research question I felt that counting made no sense and instead adopted a qualitative approach to my research. By

adopting a feminist participatory approach to qualitative research and interviews in particular, the hierarchy between the researcher and participant is broken down and the participant plays an active part in the research process through their interaction with the researcher (Letherby, 2003:83). Qualitative research rejects the notion that there is a single, objective reality or 'truth' to be discovered (Clarke, 2001:33). Given that I would be exploring a wide range of situations, it was decided that a focus group discussion would be undertaken to gain an understanding of the experiences of people who have had to make decisions regarding the care of an older relative. Originally, the research was focused on decision making rather than the overall experience of care and the discussion was intended to follow a semi-structured interview schedule which essentially outlined Tyrell et al.'s (2006) five dimensions of choice: the amount and quality of information made available to the service user; the extent to which a service user considers they are being listened to by a professional; the extent to which a service user feels they are able to express their opinions about options; the time available to service users to reflect on options before making a choice; and the possibility of being able to change their mind if the decision taken does not work out. The data from this group discussion was collected in order to assist in defining of the research questions and informing the next stage of the research. The primary influence of the focus group discussion on the subsequent direction of the research was that the process of decision making was no longer the central focus, instead it was the peculiarities of each situation that was important to the participants.

Individuals who had assisted older people to obtain information and make choices in health and social care services were actively sought to form the focus group. The recruitment of participants for the focus group aimed to include a diverse range of age, ethnicity and gender but did not aim to be fully representative as the data generated was not intended to be generalizable to a particular population. The use of a focus group at the exploratory stage was intended to enable the researcher to identify a range of perspectives. The intention was that the interactional nature of the focus group would allow participants to clarify or expand upon their contributions to the discussion in the light of points raised by other participants, thus expanding on contributions that might be left underdeveloped in an in-depth interview (Powell & Single, 1996:504). Focus group data lacks the depth of information that can be obtained from individual interviews so the themes identified from the discussion were intended to be explored further through face-to-face in-depth interviews (Gilbert, 2001:168).

The participants for the focus group were recruited through a request for volunteers in a monthly newsletter issued by Aston University where the researcher was based. It was considered likely that there would be a number of staff members who were currently, or had previously been, in the situation of helping an older relative to arrange some form of personal care. Since staff members would be able to attend the focus group in the building in which they were working, it was considered likely that attending would cause them minimal disruption. A description of the project and its aims were given to everyone who indicated an interest in participating, to ensure that individuals were aware of the nature of the project prior to volunteering to participate. The criterion for participation was that an individual had assisted an older relative in making choices in social care (although in order to achieve a greater number of participants an individual who had supported a friend through making such choices was also included). As the term social care is not often associated with informal care it was described as 'finding a little extra help in the home or arranging residential care'. The term 'care' was avoided as it is a word that is value-laden and contested. Shakespeare (2000:ix) suggests the use of the term 'help' because this can describe various acts of assistance.

In order to allow all the members of the group to contribute meaningfully to the discussion, the focus group was limited to a maximum of six participants. In total there were five respondents who were able to attend on a date convenient to all. Unfortunately, however, on the day itself, one respondent was called away to deal with an emergency with her father and so could not attend. This left only four participants, together with the researcher and one of her supervisors. The researcher's supervisor had offered to be present during the focus group discussion to provide moral support as it was my first experience of running a focus group. Once the first participant had arrived, my supervisor waited in the corridor to direct the other participants to the room. This was helpful as the participants did not all arrive at the same time as the room was difficult to find. During the discussion itself, my supervisor remained an interested listener but did not contribute other than to indicate when we were reaching the agreed time limit for the discussion. The discussion ran for almost 120 minutes and was recorded and transcribed by the researcher. During transcription the names of the participants were replaced with pseudonyms and any references to people or places that could identify the participants were removed to ensure anonymity (British Sociological Association, 2006).

Each member of the focus group had received the information sheet and was aware of the intended nature of the discussion. The participants began to discuss the issues relating to care for older people as they waited for other participants to arrive. The formal discussion began with the participants introducing themselves and outlining their care story and, having each told their story, the participants drew on common experiences to comment further. The participants' stories flowed without a need for prompting. Four of the five dimensions of care were touched on within the narratives of some of the participants but were not relevant to others. The discussion covered themes such as the gradual decline of abilities, older people's denial of a need for care, as well as the family's concerns over risk. The participants described the difficulty of involving older people in decisions regarding their care when they do not accept that the need exists. Additional aspects that were touched upon were the older person's fear of change and the way in which their world appears to shrink to their immediate environment. The participants described their own informal solutions to care and discussed the difficulties posed by distance from their relatives and the conflicts that arise within the family when trying to find a solution to care needs. Views on residential homes and sheltered accommodation were offered and the issue of funding discussed. The focus group discussion was centred on the situations in which care was arranged rather than on the process of making choices, as had been planned. The participants' narratives suggested it was the older person's situation or context that had the greatest impact on the choice of different solutions to care problems. Using the framework of decision making models would have reduced the discussion to specific elements of the care journey whereas allowing the discussion to evolve demonstrated how important it was to consider the individual's circumstances.

The variety of experiences and range of issues that were presented in the participants' narratives suggested that a highly structured approach to the face-to-face interviews would be inappropriate and would restrict participants' freedom to describe the aspects of their experience that had most impact on them. The narrative approach that was adopted in the interviews emerged from the focus group participants' eagerness to tell their stories, despite the fact that this was not the intended structure of the discussion. As Collins (1998:3.14) points out, and as I found out in the focus group, interviewees will tell their stories whether we encourage them to or not. The narratives that were offered provided perspectives that were unexpected and unforeseen and it became clear that the process of decision making was not the primary concern in care choices. This richness of data obtained in the focus group suggested that the most appropriate form of interviews to further explore the issues relating to arranging care would be a semi-structured approach where the interviewer encourages the

participants to share but does not guide the narrative with pre-set questions. The data from the focus group has been integrated with the data that was collected from the main study as the narratives portrayed similar aspects of care and a separate presentation of the data would have led to unnecessary and unhelpful repetition. The later discussions of the methods of analysis apply to both the focus group and the interview data. The focus group data were initially analysed thematically but was reconsidered once the method of narrative analysis had been developed for the analysis of the interview data. The design and methods of the main study are set out in the following sections.

Research Design of Main Study

The following sections set out the sampling strategy, ethical considerations, interview arrangements and a discussion of data collection before moving on to the next section, the selection of methods for analysis of data.

Sampling

Recruitment of participants was achieved through purposive sampling; the participants were required to be either over 70 and having received some form of personal care or under 70 and having helped to organise care for an older relative. In order to create some sort of boundary for participants it was decided that a chronological age of 70 was necessary for the care recipient to be considered an older person. It was considered that the traditional demarcation of old age is retirement age, however, the participants that we were seeking were those that had already been faced with decisions regarding care in later life and the addition of another 5 years to the lower age limit was intended to allow for the care choices to be related to changes due to ageing. Whilst people may be in need of care at a younger age, a general experience of social care was not the subject of investigation and it was important that older people be the focus. The inclusion of family members and significant others was considered important as Gilleard and Higgs (2013:368) argue that the Fourth Age is represented within third person narratives as it is ascribed a state of 'otherness'. The sampling strategy was a snowball sampling approach (Bryman, 2004:334); once contact had been made the participants were asked if they could recommend anyone else to take part in the research. Initial contacts were made through friends; two participants were recruited through the use of Aston University's volunteer panel attached to the Aston Research Centre for Healthy Ageing. Additionally I approached two private care companies but both felt that it was inappropriate for me to contact their clients. One company offered to leave my information sheets with

clients where they felt it was appropriate but this was a new company with a small client base and no participants were recruited, however, the conversation with the partners provided me with background information and an understanding of the challenges of care from the private sector perspective. The second company did lead to the recruitment of a participant as a carer volunteered to take me to visit her father-in-law in a local nursing home. I also became involved in my local older people's forum which led to the recruitment of several more participants.

Ethical Issues

Ethical approval for both studies was given by the Ethics Committee of the School for Languages and Social Sciences at Aston University. During this process, the propriety of approaching people who may be in the middle of a crisis was considered and whilst the inclusion of older people who may be frail may raise ethical concerns, there is evidence that people experiencing life-limiting illnesses may be both interested and, with the appropriate support, able to be involved in research (Beresford, 2007:311). In the spirit of justice and a commitment to collecting quality data, I felt that this research should not exclude individuals from research because of age or health deficits (Szala-Meneok, 2009:507). This appears an appropriate approach when framed in this way but felt much more intrusive in reality. I had two occasions where I was in the process of recruiting but the participants were dealing with a care crisis and so were unable to spare the time to take part. Overall recruitment was challenging because of the emotional and time-consuming nature of the care issues that the participants had to deal with. The refusal of some participants to take part in the study led me to question whether I should be approaching people at all. In common with Wilkins (1993:96), each refusal to participate felt like a catastrophe and it took some time to recover and prepare to approach other participants.

An information sheet was provided together with a consent form in order to obtain informed consent from the participants. The information sheet made it clear that participants could withdraw from the study without giving a reason (British Sociological Association, 2006). When planning the information sheet, it was discussed that once data has been collected and analysed it becomes increasingly difficult to extricate a particular participant's contribution and for this reason a deadline for the withdrawal of participation was set at six months after the date of the interview (British Psychological Society, 2010). On reflection, I believe that if any of the participants had approached me and asked to be withdrawn from the study I could have, and would have made every effort to, remove their narratives from the final report and I

would have been happy to do this at any point up to the point of submission of the thesis. The six month deadline for withdrawal is not something I would use in future research. The Information Sheet also explained that the interview would be audio-recorded but that anonymity would be achieved through the removal of identifiers and the use of pseudonyms (British Sociological Association, 2006). At the start of the interview a consent form was provided to participants and they were asked to confirm that they gave their consent not only to the recording of the interview but also for the resulting data, including verbatim quotes, to be used in subsequent research reports. The importance of the provision of appropriate amounts of information was emphasised by Baxter et al. (2008) and so careful attention was given to the wording and layout of the information sheet in particular to font type and size and line spacing as the appropriate use of white space can aid the readability of text for those with visual impairments (Szala-Meneok, 2009:511).

Participant Summary

In addition to the four narratives that were collected from the focus group, fourteen participants were interviewed. The summary below offers a view of the various situations of the participants.

| Pseudonym | Relation to care choice |
|-----------|---|
| Penny | Supported her Grandparents Mr and Mrs Cole; Mr Cole had advanced Parkinson's disease and Mrs Cole was his main carer. Penny arranged care at home and liaised with a social worker to arrange nursing home care after Mrs Cole suffered a stroke and heart attack. Penny referred to her grandparents throughout the interview as either Nan and Granddad or Mr and Mrs Cole, this language is reflected in the discussion of her narratives. |
| Sue | Supported her parents, father (Andy) recovering from cancer and mother (Maggie) living with advanced Alzheimer's. Sue arranged temporary care for her father in a convalescent home and carers once he returned home. |
| Andy | Father of Sue, caring for his wife (Maggie) who was suffering from advanced Alzheimer's disease. |
| Sheila | Cared for her father and then arranged formal care when she could no longer manage alone. |
| Jerry | Cared for his mother at home and then arranged care in a residential home. |
| Heather | Arranged care for her mother who had a broken leg and mild dementia. |
| Derek | Was living in a care home and had significant care needs. |

| Pseudonym | Relation to care choice |
|------------------|--|
| June | Had cared for her husband at home until he passed away. |
| Brendan | Was experiencing increasing health problems which were limiting his mobility. He was supported by his wife but did not yet need formal care. |
| Ken and Martha | A married couple living in a retirement village. Martha had a diagnosis of dementia and Ken had suffered several heart attacks. |
| Ellen | Ken and Martha's daughter – we had an informal conversation as I was leaving Ken and Martha's flat but not a full interview. |
| Barbara | Had cared for her mother and arranged residential care, also supported a close family friend who lived nearby. |
| Rachel | Cared for her partner with whom she 'lived together apart'. |
| Joanne | Disabled by Multiple Sclerosis, only had the use of one limb. Joanne employed her own carers directly and self-funded her care. |
| Stephen | Jointly with siblings arranged care for parents. |
| Samreet | Cared for her mother in Samreet's home. |
| Deborah | Shared story of grandmother's care and supported a friend arranging care for her mother. |
| Sally | Arranged care for her mother who wanted to continue to live at home without family. |

The Interview Experience

Oakley (1981:31) suggests that interviewing “is like a marriage, everybody knows what it is and yet behind closed doors there is a world of secrets”. This section seeks to expose some of the ‘secrets’ of the interviews undertaken in this thesis. It has been proposed that ‘feminist research begins from the premise that the nature of reality in western society is unequal and hierarchical’ (Letherby 2003:5). Historically, research has been presented as orderly, coherent and hygienic, yet all research is ideological because no one can separate themselves from their values and opinions (Letherby, 2003:5). Being reflexive and open about what we do and how we do it and the relationship between this and what is known is crucial for feminist academics as it allows others to understand the background to the claims that we are making (Letherby, 2003:5–6).

The majority of interviews were conducted at participants’ home, this allowed them to feel comfortable but for me was often a nerve-wracking experience. The interviews were designed to give little direction and began with a single ‘open’ question which depended on the information that I had regarding the participant, for example “can you tell me about your experiences of arranging care for your mother?” The aim was for the participant to take the lead and talk freely about the experiences they choose, framed in their own terms of reference, whilst I adopted the role of active listener (Gabb, 2010:7). For the majority of participants this worked well, however, in the case of Heather I felt that she would have preferred to have been presented with a list of formal questions that she could have answered succinctly and sent me on my way. With other participants I felt extremely relaxed and able to let the silences stretch out so that they could think about what they wanted to tell me but with Heather I rushed to fill the gaps and metaphorically kicked myself throughout the interview for doing so. With other participants, Jerry and Brendan in particular, I was content to sit quietly. Jerry was softly spoken and seemed to naturally pause between sentences so it felt easier to let the silences continue. Brendan struggled to catch his breath and as we had worked together over the past year I was aware of his health problems, as well as his frustration when people did not give him time to make his point.

Wilkins (1993) emphasizes the emotional nature of research and makes the point that “impersonal approaches perpetuate the myth of abstract, disembodied knowledge, and obscure the agency of the knower and their ways of knowing” (Wilkins, 1993:93). The emotional aspects of the interview interaction are important in two ways. Firstly, they alert us to the meanings and behaviours of others and they make us sensitive and able to empathise

with most participants (although as mentioned above this was not always the case). Secondly, our emotional responses have an important interpretative function as a “medium through which intuitive insight and inchoate knowledge arise, and this in turn depends on the availability of similar emotions and/or experience, whether imaginatively or actually, within our own biography ... The research experience is primarily an existential and not a cerebral matter” (Wilkins, 1993:96-97).

The role of the researcher in eliciting the story is performative and, amongst other roles, I had to perform the role of interested listener. This was particularly difficult in two cases where the participants were keen to continue the conversation but were moving away from the topic of care to a more general discussion, not related to their personal biography. The design of the interviews was expressly to allow the participants to construct their narrative as they wanted and the fact that these narratives reflected the “emotional messiness of relational and everyday lives” (Gabb, 2010:29) is to be expected and on reflection I realise that there was no need for me to be concerned that the participants were representing life as it is lived. Whilst I aimed to be an active listener I felt that when a direct question was asked, it was appropriate that, as a feminist researcher, I should answer “as fully as was required” (Oakley, 1981:47). Jerry asked me what other participants’ experiences had been and I replied that some had been traumatic whilst others had adopted a pragmatic approach that it was a problem to be dealt with. He went on to describe his mother’s transfer to a care home in exactly those terms. However, this was near the end of the interview (after over an hour of conversation) and so possibly prompted some additional narratives rather than restricting his comments. Collins (1998:3.13) makes the point that even the most unstructured interview is structured in a number of ways regardless of the existence of an interview schedule. He cites Bernard (1994) who argues, ‘any question an interviewer asks may be leading’ (Collins, 1998:3.13). Collins (1998) suggests that whilst an interviewer’s questions and comments are necessarily leading, the interviewee can always subvert such leading. This brings to mind my interview with Joanne who suffered from Multiple Sclerosis (MS). Joanne and I had been discussing her carers and the aspects that she valued and how they met her particular needs. She explained one incident where she had had an excruciatingly painful headache which was a symptom of her advanced MS. A short while later she asked me whether I knew much about MS and I explained that my eldest daughter had been diagnosed two years previously. Despite my efforts to return to discussion of Joanne’s care needs, for the rest of the interview she asked questions about my daughter and made suggestions of things which she felt might prove helpful. I knew from experience that people find it distressing to hear of a young woman with

MS but I also felt that it would have been dishonest to have withheld this fact from Joanne. I do feel that this hindered the remaining part of the interview as the discussion turned to ways in which Joanne had managed her MS, in particular her detailed account of having allergy tests and recommending that my daughter undergo similar tests as allergies and diet are considered to play an important role in the management of MS symptoms. I found it difficult to steer the conversation back to the subject of Joanne's current care arrangements.

In Collins' (1998:2.6) article he suggests that each interview is an occasion for the elicitation of many selves:

"The interview, though it may appear a single, coherent social event, is not. To the extent that the selves of both interviewer and interviewee are variously and complexly defined the interview is a carnival of voices and a concatenation of events. Even to define the interview in terms of the co-presence of interviewer and interviewee might be an oversimplification."

The interview with Rachel felt as though there was indeed a carnival of voices. Rachel was very theatrical in her storytelling and would play the part of different characters, whether a doctor or a nurse, her own parts were played with emotion, at one point her anger made me anxious as I was not sure how I should react. I thoroughly enjoyed our conversation and, although I didn't feel that I had contributed much, I did feel that we had both been entertained. Although Rachel's performance was more flamboyant than other participants, it is understood that all narratives involve a performance as the participants seek to display a sense of themselves as "the self... is a dramatic effect arising diffusely from a scene that is presented, and the characteristic issue, the crucial concern, is whether it will be credited or discredited" (Goffman, 1969:245).

In spite of this understanding that participants were managing the performance of their narrative, the concerns about intruding on people's personal stories persisted and these were often coupled with worries about exploitation. June explicitly stated how lonely she was since the death of her husband and I felt that I had turned up and was then going to abandon her. To provide June with company for as long as possible, my visit lasted for over three hours and talk turned from June's care experiences to discussion of the local older people's forum, through which we had met, and other local social groups that were active in the area. For some time afterwards I was concerned that I had upset June by pushing her to recall a distressing time in her life, but as Gabb (2010:19) asserts there is a difference between causing 'harm' and 'distress' and while talking about emotionally significant events can be distressing for some individuals this is quite distinct from being harmed.

Collins (1998:3.3) points out that all interviews have an element of exploitation as even the most well-intentioned researcher seeks to gain prestige and even promotion through publishing their research findings and as such is concerned with “the implementation of ploys, of one sort or another, through which one seeks to improve the quality of data.” This does not mean, however, that participants are completely powerless, they can choose to “limit disclosure, close down streams of thought, steer away from personal stories and redirect the narrative” (Gabb, 2010:19). Several participants commented that their interview had been a rare opportunity to talk about their experience of care. Penny stated that it was only as she was explaining the situation to me that she was realising that her grandparents were unlikely to return to their cottage to live independently. I believe that this experience of interviewing has improved my skills as a listener and I am grateful to all of my participants for sharing their stories with me.

Selection of Methods of Analysis

Whilst phenomenological studies aim to describe what all participants have in common and to reduce experiences to a description of the universal essence of a phenomenon, narrative analysis seeks to capture the detailed stories which provide a view of the life experience of a single individual (Cresswell, 2006:55–56). Importantly, narrative analysis seeks to explore how experiences are different for different people (Cresswell, 2006:57). This is particularly important in examining care choices and agency in later life. The focus group indicated that it is important to explore how the availability of choice forms part of understandings of care and the possibility of agency in later life.

Care itself is a practice that is negotiated by people ‘working together to shape, invent and adapt processes to fit everyday life’ and an understanding of this process can best be achieved by considering their life stories (Mol, 2008:5). In order to understand the complexity of the situations of the families involved in caring and choosing care for older relatives it is necessary to look at the whole picture. Narrative accounts preserve the sequential and structural features that characterise life stories (Riessman, 1993:3). Comments from participants indicate the importance of taking into account the nature of their accommodation, the comorbidity of the older person (not simply the most problematic illness at a particular point), the relationships between the older people and their family and the history of the older person. Narrative analysis permits this close examination of the overall picture.

In narrative studies there is no automatic starting or finishing points for identifying narratives or for undertaking analysis. The possibility of a variety of approaches and methods requires each researcher to explore the most appropriate method of analysis for their data (Andrews et al., 2008:1). Before considering issues of representation and transcription, it is necessary to set out the meaning of narrative analysis.

What is Narrative Analysis?

Stories in research interviews are not clearly identified and choosing where to begin and end narrative can profoundly alter its shape and meaning; these decisions underscore how much the researcher can influence the story (Riessman, 1993:18):

“Determining the boundaries of a narrative is one of the many ways that we participate in the creation of narratives, rather than “finding” them in interviews... Some narratives that develop in research interviews are clearly bounded, with clear beginnings and endings. Most personal narratives, however, like most lives, are more complex. In these cases, there are no clear rules for determining boundaries, but the analytic decision is important for it shapes interpretation and illustrates once again how we participate in the construction of the narrative that we analyse” (Riessman, 2008:41).

Narrative analysis (NA) looks at the linguistic and cultural resources that the participant’s story draws on and asks ‘Why was the story told *that* way?’ (Riessman, 1993:2). Narrative analysts interrogate intention and language, and examine how and why incidents are related as stories. Asking questions such as who was the story constructed for and why? (Riessman, 2008:11). Whilst this may not appear relevant in an interview situation where the story is clearly constructed for the interviewer, different participants seek to present different aspects of their lives depending on what they consider to be important. For example, in this research a married couple where the wife (Martha) had dementia and was cared for by her husband (Ken) discussed how at times she could have difficult moods but they spent most of the interview telling me how happy they were together and concurring that they never actually argue. During a brief conversation with their daughter after the interview I found out that the wife could be very aggressive and controlling of her husband, not wanting him to join in social activities in the retirement village. The narrative that the couple presented to me was perhaps constructed to portray themselves as they had been in the past or perhaps it was a narrative that they considered appropriate for a passing acquaintance who had no need to learn about their personal struggles. In analysing their narrative I had to be careful not to privilege their daughter’s knowledge, instead I accepted their narrative as their representation of their

experience in the same way that I did with all the other participants. The importance of representation and understandings of discourse are examined further in the following section.

Riessman (2008:22) makes the point that narratives “do not merely describe what someone does in the world but what the world does to that someone. They allow us to infer something about what it feels like to live in that story world...” Narratives do not merely refer to past experiences but create experiences for their audiences (Riessman, 2008:22). As such, narratives are representations of experiences that are recounted within the confines of a discourse. Foucault’s discussion of discourse focuses on constraint and restriction: “we could utter an infinite variety of sentences but what is surprising, in fact, we choose to speak within very narrowly confined limits” (Mills, 2003:56). This section has provided a broad view of narrative analysis and the following section explores in detail the importance of understanding that narratives are a representation of an experience and not a direct reflection.

The Importance of Representation

Within narrative analysis it is emphasised that a narrative will not be an exact report of an event. When people talk about their lives they forget, exaggerate or get things wrong and yet they are revealing the past, not as it actually was but their recollection of their experience of it (Riessman, 1993:22). When we experience an event there is a choice in what we notice, and when we recount the event later we select aspects of the experience depending on our biographies and interests (Riessman, 1993:9). When it comes to telling others of the experience, the particular aspects that we include or emphasise may vary depending on the audience to whom we are talking (Riessman, 1993:10). When the story is being told to particular people; it might take a different form than if someone else were the listener (Riessman, 1993:11). The narrative approach does not focus on the truth of the stories told by participants but instead acknowledges that a straightforward description of the data would not be possible as “it is not possible to be neutral and objective, to merely represent (as opposed to interpret) the world” (Riessman, 1993:8).

Some researchers regard representation as unproblematic; for example, some researchers emphasise “giving voice” to previously silenced groups by describing the diversity of their experience (Riessman, 1993:8). However, Riessman (1993) argues that we cannot “give voice” but we can hear voices that we record and interpret (Riessman, 1993:8). In Riessman’s (1993) and Haraway’s (1988) view, it is not possible to describe other’s experiences; this process will

always involve representational decisions at various points in the research process. These decisions are influenced by our own experience and partial view of the world.

Narratives employ shared meanings and are not a straightforward reflection of the material world but a representation of that world. The constructionist approach to meaning in representation recognizes the public, social character of language (Hall, 1997:25). It acknowledges that neither things in themselves nor the individual users of language can fix meaning in language; we construct meaning, using representational systems of concepts and signs. It is social actors who use the conceptual systems of their culture, such as the linguistic and other representational systems, to construct meaning, to make the world meaningful and to communicate about that world meaningfully to others (Hall, 1997:25). Foucault's work recognises that in certain historical moments, some people had more power to speak about some subjects than others, linking ideas of discourse to the roles of knowledge and power (Hall, 1997:42).

Whilst Foucault's ideas are drawn on to examine power relations and discourse, his is not the only approach to discourse analysis. Other approaches can be separated into formal discourse analysis and the empirical approach (McHoul & Grace 1993:27). The formal approach considers discourse in terms of text and analysis of formal linguistic methods, whilst it can be critical, in that it reads texts as socially classed, gendered and historically located, it is linked with socio-linguistics which is not the central focus of this thesis (McHoul & Grace, 1993:28). Empirical approaches consist largely of sociological forms of analysis and discourse in this tradition is frequently taken to mean human conversation and may be similar to Foucault's approach but in this tradition 'knowledge' refers to technical knowledge or know-how (McHoul & Grace, 1993:29). For the purposes of this research and understanding how narratives are shaped by discourse the critical approach developed by Foucault is appropriate. For critical discourse theorists such as Foucault the term 'discourse' refers not to language or social interaction but to relatively well-bounded areas of social knowledge (McHoul & Grace, 1993:31). A 'discourse' is whatever constrains, or enables, writing, speaking and thinking within specific historical limits (McHoul & Grace, 1993:31).

Foucault is interested analysing the way that discourse is regulated: "in every society the production of discourse is at once, controlled, selected, organised and redistributed by a certain number of procedures whose role is to ward off its powers and dangers, to gain mastery over its chance events, to evade its ponderous, formidable materiality" (Foucault, 1981:52). The structure of discourse controls what can and cannot be said and what will be

regarded as true or false. Those who are not in positions of power will not be considered to be speaking the truth (Mills, 2003:65). Truth is something which is supported materially by a whole range of practices and institutions, so even if we are asserting something which as far as we know it is 'the truth' our statements will only be judged to be 'true' if they accord with, and fit in with, all of the other statements which are authorised within our society (Mills, 2003:65).

In addition to the production of discourses being constrained by societal norms, there are other regulatory practices of exclusion that are concerned with classifying, distributing and ordering discourse to distinguish between those who are authorised to speak and those who are not; those discourses which are authorised and those which are not (Foucault, 1981:56–58). The regulation of discourse also involves practices which aim to keep particular statements in circulation and other practices which try to keep statements out of circulation (Mills, 2003:54). It is difficult to think and express oneself outside of these discursive regulations and this is why there are rituals at the beginnings of discourse; for example when people begin a conversation on the phone there are ritualised openings and closings. We often don't think about these ritualised utterances; we only notice when someone does not use them (Mills, 2003: 57).

Discourse itself structures what statements it is possible to say, the conditions under which certain statements will be considered true and appropriate (Mills, 2003:66). Foucault's work on discourse and power is useful in considering the way that we know what we know; where that information comes from; whose interests it might serve; how it is possible to think differently; in order to be able to trace the way that information that we accept as 'true' is kept in that privileged position (Mills, 2003:66).

The above discussion demonstrates that narratives are produced within discourses and with this understanding it alerts us to the way in which narratives may be constructed and constrained. The awareness of the process of representation and the ways in which power can impact on the way in which experiences are re-told enables researchers to understand how the information they are given is produced. The researcher's decisions regarding how to represent participants' narratives are discussed further in the following section that examines transcription and analysis of data.

Transcription and Analysing Transcripts

When considering subjectivity in transcription, there are many ways to prepare a transcript. Each method is only a partial representation of speech and while an audio recording may be

more selective than a video, in neither case would the entire conversation be captured: "...it must be borne in mind that the initial record – audio, or videotape or running observation is itself only a partial representation of what "actually" occurred (Mishler, 1991:48). Mishler (1991:48) advises that researchers should be wary of taking transcripts too seriously and suggests they should keep returning to the original recordings to assess the adequacy of the interpretation (Mishler, 1991:48).

When analysing transcripts, the challenge in all qualitative work is to identify similarities and collect them together to form a coherent summary (Riessman, 1993:13). As discussed previously, the anticipated response to the work inevitably shapes what gets included and excluded. When writing up the analysis the researcher should bear in mind that every text is "plurivocal, open to several readings and to several constructions" (Riessman, 1993:14). A researcher's narratives about participants' narratives are created from talk that "represents reality partially, selectively and imperfectly" (Riessman, 1993:15). Tellers select features from the "whole" experience to narrate but add other interpretative elements and the same happens with transcribing, analysing and reading. Framing discussion of the research process as representation rather than stages or perspectives emphasises that we actively make choices that can be achieved in different ways; these choices are influenced by our own social orientation (Riessman, 1993:15). Decisions are constantly made about what belongs in this representation, what should be set aside for later and how the stories fit together; the ongoing nature of this process is what makes up the process of analysis (Frank, 2010:44).

Selecting an Appropriate Approach to Narrative Analysis

Andrews et al. (2008) emphasise that there is no prescription for conducting narrative research and that each project will evolve according to the research question, the data collected and the researcher's approach to that data. When discussing various approaches to narrative analysis (NA) both Riessman (1993, 2008) and Mishler (1991) refer to Halliday's (1973) typology of language functions to explain the levels at which narratives can be analysed. Firstly, the ideational function, that is the referential meaning of what is said is defined as the way that the speaker refers to their own experience (Riessman, 1993:37); second, the interpersonal function, the role of relationships between speakers; and third, the textual function, the structure of the text and how the different parts of a text are connected syntactically and semantically, that is language rules and meanings. Meaning is conveyed on all three levels and NA provides methods for examining and relating meaning on all these levels (Riessman, 1993:21).

Taking this typology into account Riessman (2008) outlines three approaches that vary according to the level of focus on content, the unit of analysis selected and the degree of attention paid to the context of the narrative. This thesis is interested not only in the experience of older people but also those who are affected by an older person's need for care; that is the individual's experience as well as the context. As such, attention to the way that individuals and their social networks are connected is an important element of the narrative analysis. The following discussion outlines Riessman's (2008) suggested approaches to analysis and evaluates their appropriateness to this thesis.

First, thematic narrative analysis is similar to other qualitative methods such as grounded theory. This approach is most often confused with grounded theory but there are differences, especially with methods of coding (Riessman 2008). Essentially the objective of grounded theory is to generate inductively a set of stable concepts that can be used to theorise across cases; by contrast, narrative analysis is case centred (Riessman, 2008:74). Within thematic NA narratives may be defined as a bounded segment of an interview text, an extended account of a story, a bounded segment of a document or the life story of a speaker (Riessman, 2008:75). In all these approaches the analysis is concerned only with "what" is said (Riessman, 2008:73). To allow for a more extended discussion of the context of the narrative and the wider concerns of the participants, thematic analysis was considered to be too restrictive and so a broader approach was sought.

The second approach discussed by Reismann (2008) is structural analysis, based on work by Labov (1972), which forms the basis for many approaches to narrative analysis. Whilst a good starting point for understanding the way the story has been put together, it is less appropriate for this study as the attention is largely on the local/personal context and very little attention is paid to the societal context, a context which is important when considering the impact of public policy (Riessman, 2008:102). In research on ageing, examples of narrative analysis that have explicitly used a structural analysis are relatively rare (Phoenix et al., 2010:5).

The third approach is dialogical narrative analysis. According to Riessman (2008:105) a dialogical narrative analysis (DNA) is a broad and varied interpretative approach to oral narrative that makes selective use of elements of thematic and structural analysis and adds further dimensions. It interrogates how talk is interactively (dialogically) produced and performed as narrative (Riessman 2008:105). Performing identity is considered particularly important in ageing research. Phoenix et al. (2010:6) suggest that viewing age as being something that is 'performed' and 'acted out' can draw attention to what often goes

unrecognised: that is, the performative, interactive work of accomplishing age, the emotional work associated with 'becoming and being' an age and the strategies that people build and draw upon as they create and present themselves as being of a particular age (Phoenix et al., 2010:6) By viewing age as something that has been achieved successfully, attention moves from matters internal to the individual towards interactional processes (Phoenix et al., 2010:6).

Frank (2012) suggests that one of the main aims of DNA is to speak with a research participant rather than about him or her even when analysis and research reports seem to require speaking about the object of the analysis: "To practice DNA is to sustain a tension between dialogue and analysis" (Frank, 2012:34). Frank (2012:36) suggests that the narrative analyst becomes an expert after hearing multiple stories from many storytellers and discusses his experience of collecting narratives. Frank describes that what was important for him after listening to illness stories was to gather the voices he had heard and give them a more evocative force so these storytellers could hear each other, but could also be heard collectively (Frank, 2012:36).

DNA places an emphasis on the "unfinalized nature of persons" (Frank, 2012:37). On one hand, there is no ending: people tell stories in order to develop their self-understanding, and any story is likely to be revised in a subsequent telling. However, research reports have a practical need to end and by focusing on the finite number of character types, plot lines and genres it becomes possible to draw conclusions and come to an end (Frank, 2012:37).

DNA does not seek to summarize findings, indeed, the concept of "findings" is considered to be an "undialogical" word that implies ending the conversation and taking a position apart from and above it rather than being open to continuing possibilities of listening and responding to what is heard (Frank, 2012:37). DNA aims to increase people's possibilities for hearing themselves and others and seeks to expand people's sense of responsibility in how they might respond to what is heard; DNA rarely, if ever, prescribes responses (Frank, 2012:37).

In the same vein as Frank's illness stories, this project aims to collect together people's stories of caring for, by and with older people. The project does not seek to provide a solution but to explore and re-tell the way in which care is experienced by those who provide informal care for older people as well as older people themselves. The adoption of a dialogical approach

allows for the commitment of the researcher to tell the stories about older people and care and not to pass judgement but to set out those stories for others to hear.

Identifying Narratives

The exact definition of a narrative can only be decided once a good understanding of the method for analysis has been achieved. Riessman (1993) suggests undertaking analysis of a small section of text initially. I found that whilst the recognition of a narrative was a skill that developed throughout the process of analysis, I initially found it helpful to isolate a section of a narrative and identify distinct narrative clauses. This section sets out the steps that I undertook to understand the structure of a narrative.

Whilst the overall analysis was not intended to strictly follow Labov's structural analysis, the method that he provides for the identification of these clauses is helpful in determining where a narrative begins and ends (Riessman, 1993:59). I felt that this was particularly important for me as I had not undertaken NA before and wanted to become more confident in identifying narratives. Labov proposes that clauses within stories can be defined as narrative or non-narrative, a narrative matches a verbal sequence of clauses to the sequence of events which actually occurred (Mishler, 1991:78).

Labov's structural approach is described by Riessman (1993:18) as paradigmatic: "most investigators cite it, apply it, or use it as a point of departure". Labov and Waletzky (1967) frame their analysis in terms of referential and evaluative functions: how a story corresponds to the "real" world and the point intended by the narrator. Their method examines how "units of linguistic expression are connected to one another principally through a relation of temporal order" or "how can we relate the sequence of clauses in the narrative to the sequence of events inferred from the narrative?" (Mishler, 1991:77). Stories may be put together in contrasting ways and events become meaningful because of their placement in a narrative. Temporal ordering is a central problem in NA; others approach it differently but for Labov a "minimal narrative" is a "sequence of two clauses which are temporally ordered: that is a change in their order will result in a change in the temporal sequence of the semantic interpretation" (Mishler, 1991:78). In practice, narratives may include much more than pairs of temporally ordered clauses (Mishler, 1991:78).

In order to undertake analysis we need to determine whether an account is a narrative or another form of "recapitulating" experience (Mishler, 1991:79). This is done by isolating the essential narrative structure from the flow of talk but leaves the difficulty of what functions

we ascribe to other non-narrative parts of the account (Mishler, 1991:79). The key to this is the fundamental unit, defined as “a clause that cannot be moved or relocated to any other point in the account without a change in its semantic interpretation” (Mishler, 1991:80):

A I know a boy named Harry
B Another boy threw a bottle at him right in the head
C and he had to get seven stitches.

‘B’ and ‘C’ are narrative clauses temporally related. ‘A’ is a free clause that can be put after ‘B’ and ‘C’ without disturbing temporal the order. Labov (Riessman, 1993:18) argues a fully formed narrative will include six common elements: Abstract, Orientation, Complicating Action, Evaluation, Result or Resolution and Coda.

Complicating Action (CA) – the narrative itself i.e. a sequence of events

Abstract (A) – a summary of the story

Orientation (O) – where time, place, and persons are identified

Resolution (R) – what finally happened

Coda (C) – returns the speakers to the present situation

Evaluation (E) - significance and meaning of the action

The above clauses are typically placed in order from abstract to coda but this is not a strict requirement (Mishler, 1991:82). All of these clauses are optional and if one of them is absent it does not detract from the interest or power of the narrative. The power of the narrative depends on the Evaluation clause, the means used by the narrator to indicate the point of the narrative, why it was told and what the narrator is getting at (Labov 1972 p366 c/f Mishler, 1991:81). Not all narratives include these clauses and narratives are not always clearly presented in this way. In my interviews, several participants apologised for “jumping around” but as they moved on from one story to another they would remember something that related to an earlier story. This returning to a narrative emphasised particular parts of the interview which otherwise might not have stood out.

There are criticisms of Labov and Waletzky's (1967) approach to analysing the structure of a narrative. First, the invisibility of the interviewer is contrary to the feminist approach that is a fundamental part of this research. Feminist researchers are committed to recognising that how the interviewer listens, attends, encourages, interrupts, digresses and terminates responses is integral to a participants' account (Mishler, 1991:83). Second, Labov and Waletzky's (1967) focus on temporal placement is not reflected in the analysis as importance is placed on the evaluative clauses which are “free” and may appear at any point in the

narrative (Mishler, 1991:83). Despite these criticisms the application of this approach to my own data has illustrated that some form of method needs to be identified so that the data can be reduced to the main elements of the narrative and the participant's story can then be presented in a manageable format. The aim of reducing the narrative to the main elements is to reduce the risk of fragmenting the story.

From the original collection of stories, comparatively few will actually be discussed in the research report. However, before determining which stories should be included, it is important that the concept of narrative structure is fully understood: how is the narrative organised? Why does the participant develop their story this way with this listener? (Riessman, 1993:61). In order to begin to develop a deeper understanding of narratives, both Mishler (1991:103) and Riessman (1993, 2008) suggest that Labov's criteria are applied to a section of the data to identify the structure of the narrative.

A skeleton plot can be produced by including all Labov's elements to give a clearer view of an individual's narrative (Riessman, 1993:60). My first example is a section from an interview with Jerry. My contributions are indicated in brackets to avoid interrupting the flow of the narrative:

1. Well the traumatic bit was telling Mum you can't live there anymore you've got to go and live down there and and and that worried me ... quite a lot beforehand
2. and we got the doctor in (mmm) just for that event. You know he came to look at her knees (yeah) and see how they were. I had arranged with him beforehand that,
3. please would you come so that we can tell her that we've got a nice nursing home fixed up for her and that she's going to have to move down there.
4. So that, for me, that was the traumatic bit (yeah), the bit beforehand I suppose the most painful bit of the experience.
5. Kind of realising that we couldn't carry on the way we were was um,
6. well that just, it just became obvious really (yeah) and and actually the the, having a, there was a concrete line there,
7. I think B had realised that from her parents that that, that you can actually describe ... ahead of time what ... there comes a point, what the point is.
8. With Mum it was her knees, once she couldn't stand up we thought that's it she can't stay here (yeah)
9. you know, there's no point in trying to carry on because we won't be able to manage (yeah)
10. just physically we can't manage, that's when she's got to go somewhere because we can't carry on with her here.

By assigning Labov's categories to the narrative clauses, and removing the non-narrative clauses, the transcript is reduced to show the narrative elements:

1. Well the traumatic bit was telling Mum you can't live there anymore you've got to go and live down there and and and that worried me ... quite a lot beforehand (A)

2. and we got the doctor in (mmm) just for that event. You know he came to look at her knees (yeah) and see how they were. I had arranged with him beforehand that, (O)
3. please would you come so that we can tell her that we've got a nice nursing home fixed up for her and that she's going to have to move down there. (CA)
4. So that, for me, that was the traumatic bit (yeah), the bit beforehand I suppose the most painful bit of the experience. (E)
5. With Mum it was her knees, once she couldn't stand up we thought that's it she can't stay here (yeah) (CA)
6. just physically we can't manage, that's when she's got to go somewhere because we can't carry on with her here. (E)

This reduction of the text allows for a closer analysis of the meaning of specific words and phrases. By assigning the categories and identifying narrative clauses it is possible to clarify that the clauses that are removed are non-narrative and thereby justify that those that remain are the essential elements of the participant's story.

Evaluation clauses show how the narrator wants to be understood and what the point is. In evaluative clauses the teller stands back and tells how he/she has chosen to interpret it. Access to these clauses and other structures that carry meaning depends on how we as analysts create text from talk, representing speech in continuous lines compared to clauses that allow for structural analysis (Riessman, 1993:19). As well as using structure in the narrative, tellers indicate how they wish to be interpreted through the use of elongated vowels, emphasis, pitch, repetition and other devices; transcripts that neglect these features of speech miss important information (Riessman, 1993:19). In the example above, the transcript is presented in lines that are assigned according to the narrative clauses rather than pitch and emphasis since Labov's approach focuses on understanding structure. Other methods need to be considered to be able to fully take into account pitch and emphasis and repetition. Guides to NA emphasise that attention should be paid to repetition and metaphors and whilst this may be discussed as part of the methods it is not always apparent in the reporting of such analysis. An example of this is Abma et al's (2012) report exploring responsibilities in Elder Care that explored the narrative of Mr Powell, and stated that the analysis focused "on the story plot and the use of linguistic devices, including metaphors, repetition etc." (Abma et al., 2012:24). Examples of metaphors were given but not examples of repetition or other linguistic devices. This may have been due to a lack of space in the report but it raises awareness of the importance of providing examples of linguistic devices which are reported as forming a fundamental part of the approach taken.

A further element that needs to be kept in mind when analysing narrative is the use of repetition and rhythm. Riessman draws on James Gee's argument that stanzas are a universal

unit in planning speech and that poetry builds on what we do all the time (Riessman, 1993). Stanzas are a series of lines on a single topic that have a parallel structure and sound as if they go together; tending to be said at the same rate and with little hesitation between lines (Riessman, 1993:41). Riessman suggests listening to changes in pitch in order to make line breaks rather than attending to the function of a clause (Riessman, 1993:61).

Using another example from my data there is one section that came to mind immediately on reading about the importance of pitch, repetition and rhythm. When Heather was describing the arrangements she had made for her mother's care she compared the care received in a nursing home to the care that her mother now receives in her own home:

“Now that they're here and doing it and the reality is she's far more comfortable at home, in her own surroundings, what was the care home doing?
They were helping her to get up and get dressed,
the girls do that,
they were providing her with meals,
the girls do that,
they were providing her with entertainment,
the girls do that,
with more appropriate forms of entertainment.”

The repetition and rhythm emphasised that Heather felt that the care her mother was receiving now was equal or superior to the care received in the nursing home. This was an important point for Heather as social services had questioned the arrangements before her mother was discharged from the nursing home.

The above sections show that the identification of narratives can be undertaken in a methodical manner and with specific guidelines. By practising using these frameworks I have gained an awareness of what elements need to be included to form a narrative but found that by restricting the narrative to the clauses defined by Labov removes much of the detail of the narrative that helps to portray individual participants' experiences. It is for this reason that I turned to dialogical narrative analysis that would permit greater flexibility and the opportunity to question how the narrative is constructed and why participants have selected those narratives to convey their experience.

Beginning Dialogical Narrative Analysis

Having rejected the strict adherence to the structural approach of Labov, the dialogical approach to narrative analysis allows stories to “remain fuzzy at the boundaries” and so include more of the context and emotional elements of participants' speech (Frank, 2012:43).

Within dialogical analysis stories that are selected are the stories that should be told this is described this as phronesis (Frank 2012:43).

Phronesis is, first of all, the analyst's cultivated capacity to hear, from the total collection of stories, those that call out as needing to be written about (Frank, 2012:43). Selections are made based on specific values, according to Flybjerg (2001 c/f Frank 2012:43) "choices must be deemed good (or bad) in relation to certain values and interests in order for good and bad to have meaning". Importantly, phronesis is practised, it is a craft not a procedure: an iterative process of hearing stories that speak to the original research interest, then representing these stories in writing, revising story selections as the writing develops, and then revising the writing as the revised stories require (Frank, 2012:43). The analysis of the stories takes place in attempts to write (revise and rewrite) the research report (Frank, 2012:43). Within DNA it is freely admitted that the stories presented could be assembled and sorted in multiple ways: "Dialogical analysis has no interest in presenting itself as the last word" (Frank, 2010:44).

To begin a dialogical narrative analysis the researcher asks questions of the dialogue. The nature and exact wording of these questions will vary depending on the nature of the topic. Frank (2010, 2012) offers several examples and suggests these can be grouped into resource questions, circulation questions, affiliation questions, identity questions and, finally, questions about what is at stake. Rather than simply listing all the possible questions in this DNA, this section draws on the explanation of stories that Frank (2010) provides in his book "Letting stories breathe: a socio-narratology".

Frank's (2010:75) first question is what does the story make narratable? Frank (2010:75) uses the example of a story from Michael Berube's 'Life as we know it', Michael has two sons, Nick is developmentally 'normal' and Jamie has Down Syndrome. As Nick grows up stories are told of each of his milestones: taking his first step, saying his first word, etc. Jamie's milestones come so slowly that Berube says it was too easy not to tell stories about him (Frank, 2010:75). Berube's argument is that if people don't tell stories about children like Jamie then people will not hear stories about children like Jamie and will feel only the most minimal responsibility for the lives of these children: "A life that is not fully narratable is vulnerable to devaluation" (Frank, 2010:75). Certainly stories can injure people but silences imply there is no story to tell about lives such as these; this could be argued to be equally true of frail older people whose stories are not told either in policy, popular culture or anywhere outside of the private realm of the family. However, it is not just the telling of the stories that is important but the way in

which the stories are told: “Telling these stories can make lives vivid and morally recognizable” Frank (2010:75).

Frank (2010:76) points out that stories by themselves may not determine whether people have fuller or diminished lives but, by setting the terms in which lives are or are not narratable, stories create conditions for enrichment or diminishment. When Michael Berube fashions a story out of Jamie’s life, what is at stake is whether that story can enrich Jamie’s life. The core idea is that Jamie’s life is effectively invisible until a story makes that life narratable (Frank, 2010:76).

Having looked at what makes a story narratable, Frank’s (2010:77) second question is “who is holding their own in the story, but also, is the story making it more difficult for other people to hold their own?” Frank (2010:77) uses the phrase ‘holding their own’ to describe situations that begin with a person who has a degree of self-regard, someone with sufficient self-consciousness of what is valuable and worthy of respect about him or herself. This self-regard involves (at the high end) what a person is entitled to aspire to or (at the low end) what that person seeks to avoid. Holding one’s own can work up or down: either aspiring to a perceived opportunity or avoiding a threat to the value of the self (Frank, 2010:77).

The questions of who uses a story to hold their own, and how the story does that, are crucial but must always be complemented by the question of whom the story renders vulnerable; who now has an increased problem of holding their own, once the story has been told? (Frank, 2010:78). Within this research project some of the participants that arranged care offered narratives that show that they are holding their own, and in these cases could it be argued that the care recipients are then rendered vulnerable as they are not holding their own.

Connected to this idea and another useful question for this project is Frank’s (2010:81) interest in the ‘force of fear’ in the story; stories shape fears and desires and they express in narrative form what begins in bodies. Care begins in bodies and to understand the tinkering with bodies we need to listen to stories that detail this. Frank (2010 p 82) uses Harvey Sack’s simple story, “The baby cried. The mommy picked it up,” and suggests that it expresses a child’s fears of crying and no mommy being there. Frank (2010:81) argues that although people may not *master* their fears through stories, they do come to grips with their fears through stories. Stories not only express fear and desire but they also enact fear and desire (Frank, 2010:82). They are literary devices as well as performances (Frank, 2010:82).

This section has shown that DNA starts from specific questions. In particular, what makes a story narratable, who is holding their own in the story and who is consequently rendered vulnerable and finally, what the story is telling us about the storyteller's fears. These questions played a central role in the analysis of stories about care in later life and helped to determine which narratives were calling out to be included in the analysis.

Possible Endings

The ending of a dialogical narrative analysis need not be tentative but is necessarily provisional (because stories are unfinalizable). Frank (2012:49) proposes three issues to keep in mind when considering how to end a DNA: first, an analysis that has truly been a dialogue should end with appreciation for the storytellers and their art (Frank, 2012:50). Second, analysis can end with the relationships that stories instigate: who does the story bring together and who does it designate as outside its boundaries, and with what consequences for those outsiders? Finally, an ending can recognize how people's lives are affected by how they use or misuse their imagination (Frank, 2012:50). DNA gives increased audibility to some stories, recasts how other stories are understood and necessarily neglects many stories. Within my study, whilst there were a limited number of participants, their narratives were varied both in topic and in tone. There were necessarily some stories that did not relate to the specific topic of arranging care, for example, Sheila's theory that older people are helped to die as soon as relatives leave the hospital bedside, or the failure of Joanne's doctor to pass on her diagnosis of multiple sclerosis when she had her first relapse, instead waiting decades until she discovered the diagnosis accidentally. Frank (2012:50) points out that the stories that one analyst neglects is an opportunity for another analyst to continue the dialogue and these are perhaps stories that I could return to for further analysis in the future.

Organising Narratives

Organising the narratives for the final report proved problematic as I was anxious to preserve as many narratives as possible and to present them in a way that would reflect the experiences of individuals. Frank (2010:46) suggests developing a typology of stories, rendering order with what initially seems unconnected. In 'The Wounded Storyteller', Frank (1995) collected diverse stories that he identified as having three core narratives: the restitution narrative, the chaos narrative and quest narrative. Frank (2010:47) suggests that medical staff prefer that patients frame their stories as restitution narratives and staff tell patients restitution stories. These three types are not descriptions of personalities of ill

people, this typology was intended by Frank (2012:48) to help clinicians who work with the ill to hear how the three narrative types weave within any specific story that a patient tells on a particular day. Frank (2012:49) also warns of the dangers of a typology that is too restrictive may make people feel constrained to identify themselves and to finalize themselves as they may feel that their story ends within that typology. DNA seeks to assist people to become more reflective narrators of their lives (Frank, 2012:48).

In order for the data to be meaningful to policy makers and care professionals, I wanted to present the narratives in a way that would allow the telling of both the availability of choice in social care, and individuals' particular experiences. I drew on Lioness et al.'s (2003) discussion of 'within-case and across-case approaches to qualitative data analysis'. They posit that multiple accounts of common experiences will include the general context of the phenomenon in question; in addition the account of each individual will include a context of its own (Lioness et al.; 2003:871). These different contexts are important as although the element of an experience that is unique to one individual will have limited usefulness outside the interpretation of that individual's experience, this unique feature may be critical to understanding that particular person's story (Lioness et al., 2003:871).

However, Frank (2012) notes that once we focus on the broad storyline that can be recognized as underlying the plot of particular stories, there is the risk of creating yet another 'general unifying view' which individual stories are pushed into. This can occur at the expense of recognising the particularity of one individual's experience (Frank, 2012:76). By presenting a unifying view of the situations in which care choices are made and exploring the negotiations around choice it is intended to provide a narrative in which individuals can reflect their own narratives. Alongside this the presentation of particular contexts of care allows for the unique experiences of individuals to be shared.

From Research Design to Presenting Narratives

This study examines not only the experience of care of the individual, and their families, but how that experience connects with the way that agency is framed in later life and with the public policy narrative of choice. It is proposed that dialogical narrative analysis offers the most appropriate method to accommodate both the perspective of the individual and the wider societal context. There are certain elements that are considered important when examining care, particularly from a service user's point of view. The fragmentation of services presents difficulties when selecting services and traditional approaches to qualitative analysis

often fracture transcripts to enable interpretation and generalization; taking snippets of a response edited out of context. Narrative analysis seeks to maintain the sequential and structural features of a participant's story and so seeks to avoid the fragmentation that may be part of the story itself. The extent to which narrative analysis focuses on the individual or the context of the experience depends on the nature of the approach taken.

Frank (2012) uses the concept of phronesis to explain that the selection of stories is a craft and not a procedure; however, by exploring the procedure for structural analysis I believe I have a greater understanding of the flexibility involved in the craft of identifying narratives. With regard to the dialogue of the analysis itself, a few of the important and relevant questions have been set out in this chapter. During the process of analysis, stories that are similar in nature, or that refer to the same experience, were grouped together to form across-case narratives of the way in which care relationships are negotiated. Finally, the use of a dialogical narrative analysis means that the research will not seek to provide definitive answers to the research questions but rather will seek to provide ways in which stories of older people's experiences of care can be heard. The question of how older people experience care, how they make care choices and exercise agency are explored in this thesis by considering the power relations within care relationships. Narratives of older people, their families and significant others have been explored through dialogical narrative analysis that allows for consideration of the discourses within which the narratives are constructed.

The following chapters present these narratives in a sequence that reflects many experiences of care; the initial need for care, the limits of informal care, choosing formal care and finally the social imaginary of the Fourth Age. Whilst these points may reflect several participants' experiences the narratives presented here also draw on individual stories that show the unique features of particular experiences and emphasise that different situations give rise to different experiences.

Chapter Four: Negotiating Informal Care: “I kept him absolutely beautiful.”

Introduction

This chapter explores the terrain of informal care, drawing on Bowlby et al.'s (2010:7) framework of 'caringscapes' that provide a structure for exploring the 'doing' or practices of informal care. Bowlby et al. (2010:5) emphasise spatial and temporal dimensions and include in their conception of care the feelings and relationships that exist in people's mapping and shaping of their routes through life. They offer the metaphor of a landscape with mountains, valleys and areas of contrasting vegetation and environments. This envisions the varied landscapes as representing alternative future ways of life.

“As a person moves through a terrain, s/he can look ahead and plan a direction and a route across this varied landscape. They may set out on a well-trodden path to find their way barred or may leave the main route for an interesting byway. Some travellers do not plan their route but follow the main path without thinking or follow a path marked out for them by others. They may plan some sections of their journey but leave others to chance” (Bowlby et al., 2010:6).

What are not considered in this conception are the peaks and valleys or dips of the terrain. If we consider these as the changing levels of illness and impairment, then we can examine the rise and fall of care needs, whilst accepting that care is a fundamental part of life. This view of undulating care needs brings into focus the fact that there is no distinct point at which we can identify that a person needs help. As care needs increase there may be a gentle incline or difficult uphill struggles as people strive to cope; at the peak of the hill their needs become visible to those around them and help is provided, either informally or in a crisis through hospitalisation. With support, the older person may recover and as their needs reduce or subside, they move to the valley between hills where they continue their lives with their needs met privately. At the peak of the hill, one may be aware of another hill in the distance but from that perspective it is not clear how many more hills there are or how big they are. Undulating needs implies that the needs are always there, small or big, whereas the idea of fluctuating needs suggests that you are either in need or not and that you fluctuate between the two.

This chapter explores the changing relationships and negotiations within families that lead to the provision of informal care as well as what happens when the limits of informal care are reached. When discussing families the focus is on the sense of family as a set of activities rather than a static structure or set of positions (Morgan, 2013:6). Using a framework of

family practices conveys a sense of everyday life both in the notion of life-events that are experienced by a proportion of any population (such as bereavement) as well as activities that seem unremarkable and hardly worth talking about. These activities emphasise a sense of commonality of family experiences (Morgan, 2013:6).

The discussion of narratives begins by exploring the first 'bump in the road' and how families deal with older relatives' increasing need for help and support. The way in which the carer role is assigned within families is explored with consideration of Finch and Mason's (1993) framework of 'legitimate excuses' presented by those who are not able to take on the care role. The final section of this chapter examines situations where informal care breaks down and what this means for both the care giver and the care recipient.

The First Bump in the Road

This section explores the situation where older people's care needs are first acknowledged; the first bump in the road. Several participants described how gradual changes in family relationships lead to a family member becoming the main informal carer. These relationships continue through fluctuations of the older persons' health until a crisis point is reached. In academic literature these crises are often spoken about as medical issues but the narratives here suggest that there are also crises of a very personal nature, for example at a point when older people become incontinent. This very private aspect of life becomes public and for family members this can be the point where it is no longer possible to continue to keep all of the care within the family and so formal care arrangements are put in place. The meaning of formal care here is the introduction of paid care workers or the move to a nursing or care home.

Much of the analysis here draws on Finch and Mason's (1993) work on family responsibilities which provides a framework for exploring the way in which care relationships are negotiated. The analysis also draws on Bowlby et al.'s (2010) concept of 'caringscapes' which emphasise the way that relationships evolve over time. The narratives presented in this section describe both the negotiations within families and the changing nature of care relationships.

Participants describe how existing familial relationships evolve from 'caring about' family members to caring for them. Sue agreed to be interviewed to talk about her parents, Andy and Maggie. Maggie had advanced Alzheimer's disease and was cared for by Andy. The term 'carer' is a contested term as many people who provide informal care do not recognise that the tasks that they undertake are 'care giving' tasks (Larkin & Milne, 2013:27). Sue said that

her father was the main carer for her mother and Sue didn't really have anything to do with "the care side of things" but as our conversation progressed it was clear that she was very involved in the arranging of care and the support of her parents:

"I tend to spend an hour or two with them every day anyway, I mean luckily I work from home a lot so I can sort of juggle things ... it's been gradual really until, until two years ago, you just become aware that they're doing less and whereas Dad used to come and help me do DIY around the house suddenly he can't lift things so much, can't reach things or his eyesight's not so good so I start helping them but it has been a fairly gradual transition but it is this, the balancing act between taking over, I mean it would be very easy just to take over and say right, you know, I'm moving in, I'm doing the cooking, you know, you just sit there I'll look after you sort of thing and, but I don't think that would be right either so that is what I am finding most difficult is the balance between how much I do and I do find myself biting my tongue quite a lot when he's talking about what they're planning to do and I'm tempted to say, no don't do that, think of a more diplomatic way of putting it or something (laughs)."

Despite Sue's rebuttal of her role as carer she describes how she spends an hour or two with her parents; later, she mentions that she helps her mother to brush her teeth and has moved in for a short time to 'look after' her mother while her father had an operation. Sue describes the way in which her relationship with her father changed from one where he would provide her with help around the home to the current situation where she is helping him with household chores. She describes how this change was a gradual transition as her father's mobility decreased and his eyesight worsened. She also describes how she feels that she needs to balance her urge to take over all the household tasks with her parents' need to remain independent. This balance is a significant aspect of family relationships (Finch and Mason, 1993:58). The issue of power and control are particularly relevant to discussions of dependence and independence. If Sue were to take over all aspects as she suggests then she would be disempowering her father, by suppressing her urge to take over or 'biting her tongue' she is supporting her father's continued independence.

Penny was another participant who did not consider herself a carer but helped her grandmother, Mrs Cole, in the care of her grandfather who suffered from Parkinson's disease. At the time of our interview, Mr and Mrs Cole had moved into a nursing home as Mrs Cole had suffered several strokes and a heart attack. Penny described the events that had led to Mr and Mrs Cole leaving the home that they had lived in for all of their married life. Penny was very close to her grandparents and as her grandfather's care needs increased, Mrs Cole would call on Penny to help. Their home was in a rural area with poor transport links. In terms of the social model of disability, as described by Morris (2013), Mr Cole was impaired by his advanced Parkinson's disease but both he and his wife were disabled by their environment.

Originally there had been no central heating and there was only an upstairs bathroom which Mr Cole could not reach so they had a bed and a commode installed downstairs:

“Because he had been having some mobility problems for a while and he got to the point where he couldn’t really do anything. You know, my Nan was calling me, ringing me here to say can you come and help me get him off the commode. So they had facilities in the house ... things like commodes were in place the OT had arranged for some bars, you know grab rails sorry in the house and things like that but that was all the involvement. So he then, his mobility got so bad, like I say I was being called to help get him on and off the toilet, she couldn’t even do that because, you know, he was so heavy ... at this time as well I started to do a bit of cleaning for her and general sort of maintenance of the house. You know, go up there every week and sort of cleaning round to limit the stress on her as well.”

Despite the installation of the commode and other mobility aids Mrs Cole still needed some help to move her husband and would call on Penny to assist. Although Penny was the closest relative that Mrs Cole felt able to call upon she still lived at least 10 minutes away by car. Penny began spending more time at her grandparents and helped in other ways such as cleaning and general house maintenance. In doing this, Penny was making it easier for her grandmother to call on her for help as she would already have a visit scheduled, or her grandmother could postpone tasks such as washing her husband for times when she knew Penny was planning a visit.

Jerry spoke of the changing relationship with his mother as she found it increasingly difficult to cope with living alone. At the time of our interview Jerry’s mother had moved into a local care home. Prior to that, Jerry had cared for her for three years in a house that had been bought because it had a ‘granny annexe’ that she could move into. Jerry described the change in his mother’s ability that led to them moving to a home that could accommodate them both:

“Mum was still living in her house over in Westfield and finding it increasingly difficult, increasingly we were popping over to do small things, which were very inconvenient for us obviously but we didn’t mind doing it, she had a fire for example that she was having to take the ashes out and that sort of thing but bending down to do it was getting difficult, she’d sit on a little stool and struggle with it and forever talking about it. Not that it was depressing, getting her down or anything just physically getting more difficult. We spent a lot of time, myself and my brother trying to work out what to do. Then I saw an advert for this house and we came and had a look and Mum did, because it had the granny annexe and she could come and live with us. Which we hadn’t planned it long term but it seemed to be a good compromise”

As Jerry begins his narrative he describes the tasks he was undertaking to help his Mum as inconvenient but then quickly qualifies this by saying that he didn’t mind doing it. It is perhaps a concern that if he says anything negative about the caring experience it would reflect badly on his caring abilities and could be construed as not caring enough. Other participants’

narratives also expressed how challenging it is to discuss the concerns that families have about older people's changing abilities.

Stephen had been involved in the focus group discussion, he described how his parents' abilities had gradually declined and spoke about the concerns that he and his sibling had about their parents continuing to drive:

“...we were all very concerned about both of them driving ...They didn't want to give it up. I got quite angry with them I thought they were a real danger to themselves and others. My mother's car was regularly battered and there was one occasion when, apparently, she unable to find her way home, she didn't know where she was, she was driving the car and was lost ... my father ... got to the point where he couldn't really get in and out of the car without assistance or without He was convinced he was fine once he was strapped in, you know. My brother had got him an automatic which probably helped a bit but it was getting in and out of the car and his eyesight was nowhere near good enough.”

Stephen describes how his father insisted on continuing to drive for as long as possible not only because of the independence that it afforded him but also because it was part of his role as an authority figure within the family. Studies on driving cessation have shown that giving up driving impacts on an individual's quality of life but this can be mediated by the involvement of family, where families are involved prior to the individual ceasing to drive they often continue to be involved afterwards by providing lifts rather than the older person making use of public transport (Musselwhite & Shergold, 2013:95).

“My father was very keen to maintain as much authority as he could and even though he was mentally deteriorating, and he couldn't drive, which was a great blow to him because that was a loss of a kind of authority. I put him in the car and drive him around and he would insist on telling me, mile by mile, where we were, sometimes incorrectly (Laughs) ... It was just to, just to try and have some legitimacy and he, and I know my sister found it very stressful, he was a very religious man and he would insist on being taken to church and they ... there were great conflicts about trying to get him to spend money on taxis, because it cost him such an enormous sum of money to insure his car in the end and you just think, you know, you can spend, you can have three taxis a day for less than the cost of you running this car and you can build up a relationship with the taxi driver but it didn't seem to work.”

The link between driving and authority is apparent as the driver is in charge of the car and responsible for all those within it. For Stephen's father, the loss of his car could not be compensated for by the use of a taxi as the value for him was not about being able to travel from A to B but rather to be in charge. In the terms of the journey through care it was the first 'bump in the road' that suggests that the path is moving towards increased care needs and a loss of independence.

The narratives set out above show how the participants' relationships change from a conventional familial relationship to one of a carer and care recipient. In the cases described above this was a gradual, almost imperceptible, transition. This gentle change is not always the case, for some the change happens due to a sudden illness or an accident but for these participants there was time to adapt to the changes. The everyday nature of the help that is given, visiting a bit more often, helping with chores means that help can be offered and accepted without any explicit discussion. The relative of the older person becomes more and more entwined in their life and more aware of the capabilities, their needs and their preferences. These small adjustments to everyday life for both the care recipients, their carers and those who support them is very much the nature of care that is described by Mol (2008:107) in her conceptualisation of the logic of care: where care is experimental, you make adjustments to everyday routines to determine what brings improvement and what does not.

Negotiating Care Within Families

This section explores more fully the ways in which the care responsibilities are negotiated between family members. As Finch and Mason (1993) point out, care within families is a complex process of presumption, dependence, rapport and only sometimes, direct communication. Gendered assumptions that rely on notions of the natural often underpin such negotiations. The implicit character of negotiation in this form contributes to the invisibility of 'caring about' activities, particularly as undertaken by women (Bowlby et al., 2010:49).

These gendered assumptions also often mean that it is a female family member that becomes the carer despite there being multiple members of the family living within a similar distance and with a similar relationship to the older person, who could also fulfil a caring role. The following narratives explore the negotiations around family members 'assigning' the care role.

Despite the continued gendered nature of care, Finch and Mason (1993:57) found that gender was not the only factor which influenced which family member would be the person to care. There were no fixed rules within families, instead the individuals in each relationship negotiated responsibilities regarding care. Although the responsibilities needed to be met may be affected by what role another family member was or was not prepared to take, each individual would negotiate their own responsibilities. Whilst gender may influence negotiations it is not the only element that is considered, the nature and history of the relationship also play an important role; for example, a husband is not precluded from caring

for his wife simply because of his gender. Finch and Mason (1993) found that when considering care responsibilities there was no firm belief that families should be the first line of support for their members, but in this research the first place that care recipients sought or were offered help was within their family.

The variation in who undertakes care acts for a relative is a result of responsibilities being accepted through negotiation rather than as the consequence of following rules of obligation. Even people within the same family come to accept very different levels and types of responsibilities precisely because these are negotiated individually (Finch & Mason, 1993:97). This negotiation takes place all the time as people meet, talk and relate to each other, sometimes the negotiation is implicit and sometimes explicit (Finch & Mason, 1993:96). Finch and Mason (1993) make the point that it is as important to understand how people negotiate *not* taking on care roles as it is to understand how they become committed to caring. They use the concept of 'legitimate excuses' to describe how family members avoid taking on care roles. Although the term excuses implies an avoidance of obligation, Finch and Mason (1993) argue that their use of it is a non-judgemental sense to enable the examination of justificatory accounts within negotiations and how legitimacy is constructed within that context (Finch & Mason, 1993:97). It appears that an important element is the contrast between being 'unable' and 'unwilling' to help, families more readily accept an excuse as legitimate if it is presented as though you are unable rather than unwilling to help (Finch & Mason, 1993:98).

Whilst support is negotiated between offspring prepared to offer support and their parents, this is also done on a case-by-case basis for each child. There was an element of dissatisfaction expressed by some participants that other family members were presenting excuses framed as being unable to help when the participant judged the excuse as being a result of being unwilling to help.

During the conversation with Sue she mentioned that her brother, James, lived nearby but that she is mainly responsible for ensuring that her parents are supported on a day-to-day basis. For example, when I went to talk to her father, Sue was there defrosting the freezer. She left shortly after I arrived, reassuring Andy that she would be back in the early evening to turn the freezer back on. The gendered aspects of the different approaches to caring for their parents are discussed later but here I examine Sue's feeling about her brother's role in the care of their parents. I did not interview Sue's brother, James, directly but Sue spoke about his role in supporting their parents:

“...my brother, my brother is local, and on the days that he’s working from home he’ll pop in and see Dad for half an hour just for a chat and he does pop over every Sunday morning to see them. But he doesn’t help ...He never takes them out anywhere, I think they’ve been to his house once in the last year which was at Christmas time just before Christmas and he’ll book holidays and go off without telling me and I used to ring him and say look I’m going to be away this is what I’ve set up and then he used to just get all defensive ... I just thought ‘oh blow it’ and so I just sort of don’t really talk to him anymore. Every time I do try to talk to him he gets incredibly defensive: I haven’t got time, I’m so busyI think he’s so far, he’s very self-absorbed so no one in the world is busier than he and his wife are, they both lead incredibly busy lives so, that’s it really (laughs) so I’m not saying he doesn’t care but he would put both of them in a home. That’s his answer.”

Sue describes how she used to feel that she should liaise with her brother when she needed to be away for work so that there would be someone available if their parents needed support or fell ill. It seemed that James was not able to cope with this role and would get defensive if he felt that there was an expectation that he should take over the care. He did regularly visit his parents but as a social visit rather than to provide care. Sue suggested that her brother and his wife are just too busy and would rather put Andy and Maggie in a home.

Although Sue was scathing of her brother’s lack of involvement in the care of their parents, Andy did not consider that James was neglectful in any way. Finch and Mason (1993) suggest that in order to justify a lower level of support than other family members an individual negotiates by constructing ‘excuses’ which they must seek to have accepted. Finch and Mason (1993:113) state that to have your excuse accepted you must have a prior claim on your time or resources. There needs to be some form of ‘public’ acceptance, this may not necessarily be discussed but something that everyone knows. In James’ situation his public claim on his time was his job, which he appeared to emphasise in many different ways through his claim of being ‘busy’. A second element that is required in having an excuse accepted as legitimate is that you need to get yourself accepted as someone who does not wilfully avoid responsibilities (Finch & Mason, 1993:114). In Sue’s view, James sets the limits to his responsibility through his weekly visits to his parents. I spoke to Andy about his children and mentioned that Sue seemed to do “a lot of sorting things out”:

“She does a lot for us yes, a whole lot. If it’s things that I should be doing she gives me a nudge and I get them done so we work quite well, she’s my aide memoire. But no, my son would help if he could but he lives in Westbury with his wife and daughter but he’s got a hell of a responsible job and he comes down to see us every Sunday morning. He brings in the croissant for breakfast - we sit and have a cup of coffee and put the world to rights but his area of operation is most of Europe and some bits of the Far East so he’s constantly on the phone or organising something so he couldn’t devote a lot of time to us. Not without serious interference with his job and that wouldn’t be fair.”

Whilst Andy considers that it would not be fair to expect his son to do more, his daughter, Sue, is self-employed and so not entitled to paid holidays or sick leave. She is also single and owns her home although her two children are not entirely dependent on her, the youngest is still at University, and they presumably still require some support. There appears to be an assumption that because Sue is a woman she will 'naturally' accommodate the additional care responsibilities. This assumption is not only on the part of the parents and her brother but it also appears that Sue herself does not dispute this role. Whilst she comments on her other responsibilities she does not seek to use these as an excuse to reduce her care role:

"I find it exhausting so I'm not surprised Dad's tired all the time and a few weeks ago I said to him, you know, look do you want me to move in? Do you want me to be here every day? Do you want to pay me as your carer? And but he can't, he can't afford that, he hasn't got the funds, because I need to work, I have to be paid by somebody unfortunately so he's supposedly at the moment doing an assessment but every time I ask him how the assessment's going he changes the subject but I just thought if I could get him to focus on what he's finding difficult then we could get somebody in to help but they have a cleaner once a week who does the hoovering and the dusting and the polishing and cleaning the bathrooms and the toilets and things like that. "

Whilst it would have been acceptable for Sue to use her situation as a legitimate excuse Finch and Mason (1993:112) found that a lack of resources, financial or otherwise are not *always* used as a way of avoiding helping. As with other negotiations around proffered 'excuses' there are a variety of reasons why an individual would or would not be prepared to offer help to a relative, sometimes people manipulate resources to be able to help in situations where it may be perfectly reasonable to claim inability. It seems that this is what Sue is doing; she manages her work around her parents in order to provide the help that they need. The gendered aspect to the roles of Sue and her brother are clear. Sue undertakes the supportive role and the day-to-day tasks of ensuring that the household runs smoothly, doing additional shopping when needed and defrosting the freezer and her brother's role is to visit on a Sunday so that he and his father can "put the world to rights".

Another participant who negotiated care with a sibling was Jerry. In Jerry's case, the siblings were two brothers, Jerry was married but had no children whereas his brother did have children. Jerry began our conversation by explaining that he had struggled with a change in management at his job as a college lecturer and because he had decided to take a career break he was in a better position than his brother to take on the role as carer to his mother. In some aspects of the care decisions the brothers worked together but it was Jerry who took care of his mother's finances and later her care home costs as well as the day to day aspects of

care. However, Jerry felt that his brother did not understand the care that both he and his mother needed:

“... he lives over in Pinford so he’s not very far away, er I think he, I’m not sure if they, maybe a few years back they may have, they did come and live here for a couple of weeks I think, I suppose Mum must have been here then so I suppose they were doing it then before things got too demanding I think but I think when it started getting more difficult I think he just felt he wouldn’t be able to cope with it now. The situation now is that she’s, Mum is in a nursing home about 3 miles down the road so I can pop down and see her quite frequently, he generally comes over to see her once a week on a Thursday and he brings his wife along sometimes, he would come over here to see her regularly as well, the two of them would come over here and the, that’s right, the plan was that they would come here on a Thursday for instance and take Mum out or look after her and give us a break but it didn’t, it was ok but it didn’t quite work because well we felt that if they were here over lunch time perhaps we ought to offer to give them lunch and that sort of thing.”

In Jerry’s view, his brother did not seem to understand that when visiting his mother at Jerry’s house he was meant to take over the care role. He appeared to see it as a visit to both his mother and his brother, perhaps because he could not accept the change in his mother’s situation. Finch and Mason’s (1993:134) survey found that being in a situation where you have to ask for support is undesirable and that a “potential donor has some responsibility to avert the difficulties by taking the initiative to make an offer”. Jerry’s brother may have thought that Jerry was not in need of any help as Jerry made the care work seem so manageable that an outsider could not see what else might be needed. Jerry spoke about his brother visiting their mother, both in the home and at Jerry’s house:

“You know I’ve got my own things to deal with as well and actually the important thing for me when I’m down there is to be sitting there talking to her because that’s why I’m there and that’s what she wants. My brother doesn’t quite see it that way because I’m sure he goes down for an hour and spends half his time going round, in the office or something looking for people, you know, can you do something about whatever it is or, I think, and it was the same, a similar situation when he came here to visit when she was living here. He, he’d be quite happy to go out and cut the grass for me to save me the job of having to cut the grass. Doesn’t quite see that that’s not the point that you are here, and I’m doing that whereas I think my brother just doesn’t, wouldn’t want to spend that sort of time, just chatting about nothing, you know.”

The fact that Jerry’s brother appears to prefer to talk to the care staff during his visits to the care home also suggests that he is struggling to accept the changes in his mother. However, he is continuing to ‘display’ his familial relationship by ensuring that the care home staff are aware that he makes regular visits to his mother. Finch (2007:72) suggests that individuals may feel a need to *display* family when there is a change in circumstances, for example when a parent becomes much more dependent. The need arises as, although the ‘membership’ does

not change, individual identities are changing and the family-like qualities of relationships will need to be redefined, renegotiated and actively demonstrated. In principle this can apply to any relationship in any family and the displays are linked to the intensity of the changes within the family.

Jerry suggests that his brother might also feel a bit left out of the care relationship. This was mentioned in respect of his mother's finances:

"I can feel honestly that I've done the best I can with her money as being responsible for her money and also it hasn't happened yet, and pray to god it never does, but if there's any disagreement with my brother who is also equally responsible for it and then I've got chapter and verse on what happened and he doesn't know about it very much. Feels a bit left out sometimes I think that I'm just in charge of it and doing it and he doesn't know what's happening but it's not so bad now but it was quite complicated at one stage just to try and he wouldn't want me to sit down for an hour or two and explain everything about it."

Whilst Jerry felt that his brother could have helped more on the care visits there did not appear to be any animosity between them. Jerry spoke about how his mother had given himself and his brother some money after the sale of her house and that Jerry's brother had a greater need of the money than Jerry did. This also suggests that Jerry's brother had his 'excuse' of family commitments accepted as legitimate by Jerry as his mother. Finch (2007) also suggests that people want to present a family that 'works', although some participants did criticise their relatives for not being supportive enough, none of them suggested that their relatives did not care at all.

In another example of family relationships and caring negotiations, a granddaughter became the main contact with the social worker dealing with her grandparents' care. Penny spoke about how the role had fallen to her rather than to her mother or her uncle. Her mother and uncle both lived a long way away but in addition to that they were happy for Penny to take on the role:

"Mum went off on holiday, in the middle of it, which we did fall out about, we did fall out about it and that's where she'll say that I am too involved and that perhaps Granddad should have just gone straight into respite which maybe he should have done but I couldn't guarantee that they weren't going to be split up, I couldn't guarantee that. I was worried for him going in there on his own. We had a meeting with the social worker and it was quite an important meeting ... and it was a decision that had to be made, quite an important one and I rung my Mum, she couldn't speak, or she wasn't available and I rang my uncle and he'd gone out and not taken his mobile phone with him and I had to make that decision on my own but then I did. That's the way it goes, I made the decision and I did the best I thought possible I - And they're quite happy for you to deal with all of that?"

... Yeah, they are. They are but then they tell me that I am too involved. Sorry, kind of lived and breathed it, you know, and at times I felt like I was going crazy ... I just felt I was beating my head against a brick wall and you know they've done what they think is best and I feel like I'm being mean at the moment by saying that but it's a true reflection on what happened. Maybe they aren't as close to my Nan and Granddad as I am, I know that's weird because it's their children but maybe they're not. Maybe they have the ability to step back from it, I suppose if you live that far away you can detach yourself ... if you're miles away you can't be there in 10 minutes whereas I am the one here."

These justifications, or 'legitimate excuses' (Finch & Mason, 1993) that have successfully been argued as a reason for the inability of an individual to provide care have been shown to be employment, other family commitments and geography. The way in which the negotiations within families took place are not observable over the short term but it appears that the family member that did accept the role of care provider or care organiser did so willingly and without concern over the emotional and physical cost to themselves.

In contrast to these situations where there is one member of an extended family who is prepared to step in and take charge of the care, there was a participant who as an only child, did not have the possibility of sharing the care of her parents. Sheila was very open about the fact that difficulties in her relationship with her parents in childhood had an impact on her attitude towards her role as carer for her parents in later life. She described how she felt that her mother resented her and she described her father as a 'Victorian type' father who was very strict and not easily pleased. She described how she did not want to care for her Mother after she had a major stroke:

"The year before she had me she had a son who died at birth so she had two children ... and they said after me that they would sterilize her whether she had a live birth or not you see, the problem there was she then blamed me for the rest of my life for not being a boy. The first one dying you see ... you know she went through all that trouble and all she had was me, because she had this old fashioned idea that you're not a good wife unless you give your husband a son.

I- you wouldn't say you were close then.

Neither of them, no. Well she always resented me for not being a boy, she always resented me because of my dyslexia which wasn't known then. She had her stroke in '95, February '95, Valentine's day because I was going out with Rod that night and I had the phone call about 4.30 in the afternoon saying Dad had come home and found mother collapsed, so of course in those days you didn't all have mobile phones so I always remember that ... It was a massive stroke. Dad wanted her home, hang on a minute Dad, because I was working and I'd got me gentleman friend, I was living just up the road, who is going to be looking after her? She's doubly incontinent, she can't feed herself, who is going to? Oh I'll manage, I'll manage like bloody hell you'll manage, of course you won't manage. Oh well we can do it between us... hang on a minute Dad. I worked at Linebrough for ten years I ended up as assistant buyer for all the material for the factory which meant I had dealings with both the office staff and

the factory staff. The factory was mainly piece work and it was mainly women, because I always used their toilet because there was always a laugh and a joke going on in their loo. The office girls were always too busy preening themselves, you know, and most of those women were the sole breadwinners they'd either got sick or invalid parents, sick or invalid husbands, sick or invalid child most of them were the sole breadwinners looking after them and I saw what it did to them, I swore then that it's not going to happen to me. You go in any old cemetery and you'll see a grave with the old man died in their eighties and next to it there's the maiden daughter, because she's still got their surname, in her forties about six months to a year two years at the most after that, they'd only worked her to death.

So we had this argument and I said no I am not prepared to give up my life, you know, because I'd got me own home and I'd got Rod and working for Linebrough, I wasn't prepared to give up my life to look after mother because you see I never felt I owed any loyalty or anything to my parents ... Now my father, because he'd been a heavy smoker and he'd always ate a lot of butter, this vein in his neck clogged up, instead of the blood flowing through it was like spurting through, sort of thing, which were causing bouts of confusion and whatnot, when they assessed my father they said no he couldn't have an operation ... my prime concern then was the house although I'd got me own flat I thought I've earned that house you know, I've earned that house you know the way they've treated me, the parents they were to me, and now if he had a stroke like mother did and got put in a nursing home that house is going to be sold to pay for that. I thought sod that I'll come and look after you Dad."

Sheila described her experience at work where she saw the impact that caring for relatives had on other women, given her own difficult relationship with her parents, led to her resisting the role of carer for her mother. Arksey and Glendinning (2008:8) found that decisions about whether to take on a care role are influenced by the extent to which an individual sees themselves as a carer or a worker. Sheila was aware that her refusal to take on the care role was against expectations but was not prepared to forego her job and her happiness with her partner. Once her father became ill, Sheila's circumstances had changed and she also was aware that the family home would need to be sold to pay for care if she did not take on the role. This narrative contradicts the understanding that rights and commitments are an inappropriate way of thinking about family life (Finch & Mason, 1993:166). Sheila is asserting her right to continue her working life and maintain her independence. There is a strong resistance to the idea that we can expect our children to look after us and in Sheila's case she was not prepared to give up her freedom and independence to care for her mother. Although her situation was different when her father came to need care, the reason for her providing care was not payment for past care but anticipation of future reward. Indeed, it could be argued that withholding care from her mother was reparation of past neglect. Sheila had spoken at length about her childhood and her difficulties with her parents and she was the only one of the participants that presented a problematic history with the person she had cared for. This is possibly due to other participants being concerned about presenting a good

impression of themselves and concerns that any negative comments might be construed as a sign of not caring. Sheila spoke about her father's aggressive behaviour at other points in the interview and was very open about the fact that she felt her mother had not supported her or defended Sheila in the face of her father's anger. By being open about the poor quality of her family relationships Sheila was supporting her claim that she was justified in refusing to care for her mother as her mother had not cared for her. Sheila's willingness to care for her father in order to protect her inheritance exemplifies the point made by Sevenhuijsen (1998:20) that caring for others can stem from less noble motives than protection of vulnerable individuals. Sheila's narrative also illustrates that current care arrangements are dependent on previous experiences of care, and suggests that our own imagined Fourth Age will also be influenced by our previous experiences of care.

This section shows how negotiations tend to result in one family member taking the lead role in care for older relatives. Where one member of an older couple is caring for the other, a younger family member may monitor the couple and be ready to step in and assist if needed. Gendered assumptions about women as 'natural' carers appear to be as prevalent now as when Finch and Mason undertook their research in 1993. Despite the fact that Sue runs her own business, her brother's employment is held in higher esteem and is considered a 'legitimate excuse' for him being unable to undertake care for his parents. Being unable rather than being unwilling is still the way most participants framed care, Sheila was an exception and spoke about her unwillingness to care for her mother, despite being aware that this was expected of her as the only child. This resistance to gendered expectations was set against the backdrop of a difficult relationship with both of her parents. Whilst care is not based on obligation or reciprocating, the previous quality of the familial relationship may play a role in the willingness of individuals to offer to provide care.

Informal Care in 'Non-Traditional' Families

In current western societies the traditional family, a heterosexual married couple with children, is becoming less common. Increasingly, the families that will be negotiating the care of an older person may be part of a step-family or a partner rather than a spouse. These important social changes have implications for the way that informal care is negotiated; roles that were previously considered 'natural' may require explicit mediation. Rachel described how she cared for her partner with whom she had 'lived together apart' for several years. This situation proved problematic in both negotiations with family and with health care professionals who appeared to conceive of familial roles along traditional lines.

To start the conversation I asked Rachel a general question for clarification: I believe you cared for your partner?

“Well no he wasn’t my partner we didn’t live together. We were extremely fond of each other, he’d stay here some nights, I’d stay at his place, it just depended and we were like that for 8 years, 9 years and then he got cancer and it was a shock, a terrible shock really cos he’s one of these people, you know, he goes to the dentist and the dentist says oh I’ve got to do a filling, do you want anything? Yeah everything, anything!”

She describes her difficulty in persuading Stefan to accept that he needed to seek medical attention but once he did he was diagnosed with cancer. There were problems with the wider family as Rachel felt they should know about Stefan’s illness but his sons disagreed. The fact that Rachel was not married to Stefan reduced her authority within the family. The implicit understandings with wider family members that were present in the traditional families had perhaps not had enough time to develop in the eight years of Rachel and Stefan’s relationship.

As Stefan’s treatment progressed Rachel spoke about difficulties with the health professionals:

“... there was just something about this one nurse... I think she found out that I wasn’t Stefan’s wife so that made it worse, you see, and she used to look at me as though I was some dirt or something which really irritated me because we didn’t live together, we weren’t like that...No, no I loved Stefan it was just, we got on so well we had some wonderful happy times together but I wouldn’t marry him”

In this narrative, that Rachel does not describe any specific action or comment by the nurse, just ‘a look’, suggests that this may have been an “unconscious phantasy” (Davenhill, 2007:13), a memory influenced by the internal meaning given to the event by Rachel. Her earlier language “we weren’t ‘like that’” suggests that she might have been uncomfortable with the idea of living together outside of marriage.

Rachel continued to care for Stefan but asserted that she “got no thanks for it, the sons thought I was interfering and whatever.” She explained that the problems with Stefan’s sons continued when they arranged to move him to a nursing home without consulting her:

“They waited, I went to a friend’s funeral when I came back he wasn’t there. The son phoned me up, he says, we’ve had him taken into the hospital, they only keep them in that place about a fortnight and after that fortnight they have to go to a nursing home or back home. [the sons arranged for Stefan to go into a care home] So anyway, when I knew he was going to a home I said that’s it, I’m not his carer anymore now. I’ll still go and see him but I won’t be his carer anymore.”

Rachel spoke about how hard it had been to be Stefan’s carer and how her own children were very supportive:

“it was hard going and my son used to collect me occasionally on a Wednesday and take me to his cottage in Wales (oh nice) and it was a case of going up there to do things so, you know, come with me Mum, take a break, he says it’ll give you a break but there was always a ding dong about them looking after him for that day ... but anyway as I say it was terrible really. And by the end of the three years, so I was absolutely, it took me ages, it took me a good twelve months after he died to feel anything like myself again.”

This narrative from Rachel sets out the care relationship of a couple who started their relationship in later life and ‘lived apart together.’ The fact that the relationship had only been in place for eight or nine years appears to have had a significant effect on the negotiations around care. The relationship between Rachel and Stefan’s sons was very different than if they had lived together whilst the children were still dependent and living at home.

Negotiating with non-family members who are adults cannot proceed in the same implicit way as negotiations with family. The understandings around which members of the wider family should be told of Stefan’s illness had not been discussed and appeared to cause friction between Rachel and Stefan’s sons. While we only have Rachel’s side of the story, it is possible that Stefan’s sons were seeking to protect Rachel from the physical and emotional tasks of caring or that they felt that she was intruding on their care for their father. The narrative does, however, highlight the different approaches to care in non-traditional families with shorter histories than traditional families.

Having seen how family relationships evolve over time we now turn to situations where the family carer struggles to cope with the demands of care.

The Limits of Informal Care

Returning to the metaphor of undulating care, there are situations where the care needs of the older person become a hill that is just too high and too steep to conquer. There are situations where the informal carer simply cannot continue to provide care unassisted.

Jerry and his wife, Beryl, had experience of care provision as Beryl’s mother had suffered from Multiple Sclerosis and had severe care needs. This experience led to them making a decision that once Jerry’s mother could no longer stand unaided then they would not be able to continue to care for her in their home. Superficially this appears to be a discrete line drawn to place a limit on care but when Jerry explained what that meant in day to day terms, the necessity of placing a limit to care became much clearer:

“The only problem was Mum’s knees I mean mentally and physically she’s quite ok really she’s got dementia now and it was coming on a bit then but her mobility was

the problem and she was falling and so I was strong enough to lift her when she'd fallen down. I could, probably it's not in health and safety terms advisable but what else can you do, call an ambulance and wait for an hour while she's lying on the floor and all the rest of it and then you know. I could work out ways to get her up from wherever she was, and struggled but it was her knees going that was and still is the main problem with her it's just her mobility. In the end we got a doorbell, a wireless doorbell button that she could push and that was when, the other thing we did was effectively a baby monitor, one that you could listen to, she didn't know it was there but I could have it by the bed upstairs and we could hear if she was moving about or trying to or had a fall or anything you know if she called out we could hear it and she didn't know we'd got this there but that was quite useful but it did mean in the end that I was getting up several times a night every night and that's seven days a week because there's nobody else so in the end I had to have a break ... we came to the conclusion in the end that we couldn't carry on because she, well we thought once she doesn't get weight bearing and she just can't get up and confidently move around then that would be the point where we wouldn't be able to carry on looking after her really. So she had an injection in her knees from the doctor once which did perk her up for a few months, but he said I can't, you can't do it anymore, the one was just about as much as he thought she could get, to manage. Her knees were unpredictable really, you know, she, at one stage she could get up and she could move about and then suddenly she'd say, she'd sort of realise that one was going to give way or something and within, you know, a fraction of a second she'd be on the floor and it would just happen. She'd have no warning that it would come, or that they were wobbly or not able to hold her weight or anything it just seemed to be very sudden. Of course we were 24 hours a day we were wondering is she alright? What's she trying to do now? And is she alright?"

Jerry did compare the experience of being 'on call' twenty-four hours a day to that of caring for an infant:

"...sometimes it was six times a night the bell would go and, I don't get nightmares about it but it was a bit like having children, I don't know we haven't had children so I can't say but (laughs) except that I think we did compare it really with having a baby that wakes up during the night, that sort of thing but, but we felt that the crucial thing about children is that they are, you know things will get better. You do get satisfaction out of it and you are putting, what you are putting in you know is improving, things get better and better and you get that personal relationship building up whereas all we could see was the relationship was deteriorating, her condition was and the relationship was because she couldn't, she was less able to do anything or be interested in things."

Wood (2007:276) suggests that caring for a relative with dementia is similar to the preoccupation that a mother feels for her new baby, where at first the baby seems like part of herself. This is not quite the case for Jerry but there is a similarity with the participants in Wood's (2007) research where they all report that they are thinking all the time whether the person that they care for is alright, even when their relative goes for respite care the worry does not stop. In Jerry's case there was an opportunity to consider where the limit to his ability to care lay. Although he did have a difficult time in caring for his mother, he described

it as manageable in the short term. For other participants the limit to care arose because of situations that they could not manage.

As Jerry was clear about the point at which he would no longer be able to care for his mother he was able to begin to search for alternative arrangements before the limit of informal care was reached. There was a distinct difference in experiences where participants were able to undertake this sort of advanced planning and situations where a crisis was reached and had to be solved urgently.

In exploring older people's access to information about care services, Baxter and Glendinning (2011) make the point that people with gradually increasing needs try to remain independent and so do not engage with social care professionals whereas those with a sudden onset of disability, for example, from a stroke or accident, will receive information and support on discharge from hospital (Baxter and Glendinning, 2011:278). The narratives offered in this research suggest a different scenario where informal care has been undertaken by family members and the crisis that arises is not a medical problem. Several of these stories relate to the taboo subject of toileting. This move of toileting from a private action to a public event seems to open the door to formal care services. Twigg (1999:392) points out that different parts of the body have different degrees of privacy attached to them, in particular the genitals are usually off limits. The failure of the ageing body to control the expulsion of excrement moves this intensely personal and private aspect of life into the public domain. In Mary Douglas's (1966) work, the body is seen as a natural symbol which different societies use to make classifications between what they consider to be pure/polluted, clean/dirty. Orifices are especially potent because of the way that body products must cross orifices in order to enter the social world, where they may be disruptive and have to be appropriately managed (Howson, 2013:96).

The narratives offered by participants and set out below show that the topic of toileting is an important element of care and one that is emotionally demanding but, above all, it is the physical exertion that comes with caring for someone who is incontinent that comes across. The carers that I spoke to did not display disgust at the incontinence of their loved ones but they did struggle with the physical aspects of cleaning an adult.

June described how a bout of gastroenteritis led to her husband being admitted to hospital. She had been coping with keeping him clean but became concerned that because of his previous heart problems the severity of the attack might be putting a strain on his heart:

“He never ever had digestion problems, he could eat anything he never had indigestion he never was constipated but one night he had this most chronic diarrhoea in the night and I thought wow this is bad and he had very bad abdominal pain, we were in a mess everywhere and I thought well what do I do? This is serious so I called the paramedics and I had two ladies who were not very good because I said I didn’t want him to go to hospital that I just wanted a check out that he wasn’t going to get heart failure or something. I could cope with everything and they said well no you don’t have a choice. I sent him in well, fit and well, apart, he had gastroenteritis, now I did not go in with him. I know it was a mistake but I had been up all night, it was 4 o’clock, the bathroom was full of poo everywhere, the bed was, I felt all mucky and the paramedic ladies weren’t nice. They said, we’ve got to go, we’ve got to go. I thought I can’t go that quick and I would have needed a drink, I don’t mean alcoholic (laughs) (no) cos I was taking the car, you know and I just felt absolutely exhausted and I thought I can’t go and stay in A and E so what I did was I went, I went, I cleared it all up and I went and had a couple of hours’ sleep.”

Later in the interview June returned to the story of the paramedics:

“Well I think his temperature was up, which it goes up, I, actually I was exhausted when they come at 3 o’clock if you can imagine

I: I can imagine

I should have been tougher; they were in so much of a hurry. They didn’t want to wait while I got his dressing gown out the cupboard because he’d messed up one dressing gown and he’s got a clean one in the cupboard and I had to go and get. I said I don’t want him going in that dressing gown because it’s got poo down the back, you know, and they even didn’t want me to clean him up before they went because I had to keep using wipes on his bottom because he was always very fussy, I kept him absolutely beautiful. He didn’t have one mark on his body and with his feet were perfect but I did his own nails and everything”

For June this event had been very emotional. She explained that she did not feel that she had a choice and that the paramedics had gone against her wishes by taking him into hospital. It is at these crisis points that choice is removed. The paramedics would have assessed that the risk of leaving June’s husband at home was not acceptable, possibly June looked exhausted and the paramedics may have considered that they were doing the best for her as well. In June’s eyes she had made “a mistake” by not going with her husband in the ambulance but she was clearly exhausted. This was an example of Tronto’s (1993) responsiveness in care where the care giver must take care of their own needs to ensure that they are able to continue to care. June recognised her own needs by saying that she needed to stop and have a drink but she feels guilty for then going on to sleep and later speaks about having missed a phone call from the hospital because she was resting.

The medical knowledge of the paramedics gave them the power to disregard June’s wishes to the extent that she was not even able to change his dressing gown. Their refusal to allow him to change and arrive at hospital in a more dignified state was particularly distressing for June

as she took pride in her care work: “I kept him absolutely beautiful.” Her mention of “doing his nails” suggested that June placed her care work on a par with professional care work. As her husband was a diabetic any work on his feet would have been undertaken by a trained podiatrist, this is considered a skilled profession above nursing in the hierarchy of care as it does not deal with bodily fluids and is often undertaken by men (Wolkowitz, 2006:154). Different forms of care are afforded different statuses and these differentiations put unskilled care givers further down the hierarchy than professionals such as doctors and others who identify a need for care or plan its provision (Wolkowitz, 2006:153). The term ‘kept’ in June’s phrase of “I kept him absolutely beautiful” can be ascribed two meanings: kept in terms of ‘well-kept’, the practice of keeping things neat and well-maintained but also kept in terms of continued, she continued to keep him well-groomed implying that she was maintaining a particular element of his identity.

Penny also described the issue of incontinence as being a particular difficulty for her grandmother, as Mr Cole’s Parkinson’s disease meant that, at times, he was doubly incontinent:

“At this point, then the care package was stepped up so I think they were then having two care visits a day. One in the morning, one in the evening but Nan was still having to do all the in-between stuff. On and off the commode and the thing was, about my granddad, he’s doubly incontinent too ... it could be 20 times a day he could just go for a poo all down his legs ...
I - so she was washing him then?
Yes well she just had to, she has to do it all herself, hold him up and wash poo off and then do all the subsequent washing from that and that was just, you know, no pads or anything, he’d just wee or poo, bless him, he couldn’t help it ... and she was doing this probably, seven or eight, or nine, ten times a day.”

Penny suggested that it was the physical strain that led to her grandmother’s health deteriorating and the subsequent move of both grandparents into a care home. In all these stories the cleaning is mainly undertaken by a spouse. Penny helped her grandfather off the commode and supported him whilst Mrs Cole cleaned him. It appears that the intimate nature of the marriage makes this ‘dirty work’ easier to manage, perhaps because a spouse is more familiar with seeing and touching their partner’s bodies than anyone else. Twigg (2000:143) discusses dealing with dirt and disgust in her examination of carework as bodywork. She draws on Miller’s (1997) analysis of disgust where he argues that Douglas’s concept of matter out of place does not fully explain the squeamishness of responses to dirt, in particular other people’s dirt. Miller (1997) argues that the rules relating to disgust mark the boundary of the self, our capacity for disgust at our own dirt is limited (c/f Twigg,

200:143). In intimate relationships this boundary is relaxed as a necessary part of a sexual relationship (Twigg, 2000:143). As such the history of a sexual relationship could be argued to help in the suspension of disgust when dealing with a spouse or partner's incontinence.

In situations where the carer is not a spouse, toileting becomes particularly problematic. Sheila's story also linked the difficulty in dealing with toileting to the introduction of formal care. Sheila was very open (and displayed a great sense of humour) in talking about her difficulties in dealing with her father:

"I mean, towards the end of my father's life when he was shitting constantly through the eye of a needle although he wasn't eating anything. I just couldn't cope with it, I had to phone a friend she'd done nursing time in her youth she used to come and do it ... I got up the one morning, walked out the bedroom, and my bedroom door was there the bathroom door was there it was wide open, he was sitting on the toilet and you've never seen so much shit in all your life it was everywhere. Even when he died the first thing I did was change the toilet seat, put me marigolds on unscrewed, and do you know when I unscrewed the toilet seat there was even shit inside the screw and I looked at it oh I can't..... I went downstairs I phoned my friend, I don't why she wasn't there but she said she couldn't come for a couple of hours so I went through the phone book and found social services, phoned half a dozen phone calls because you have to get the right team don't you for the right area, I said to them I mean I don't mind looking after him I said but I cannot cope with the shit I cannot cope with it, right she said right give me name and address and we'll put you down on the waiting list what do you mean waiting, list well we'll come and assess you, I said how long is this waiting list she said it's about eighteen months, I said I will tell you what I will do, I am going upstairs now I am going to pack my suitcase I'm going off to the doctors, I am going to put my house keys on the counter of the doctors receptionist, I am going to tell her what I've done and you and the doctor can sort it out between you I'm off. Obviously there was something in the tone of voice, three days I'd got a care package, two women came in the morning to get him up and bath him and two came in the evening to change the incontinence pads and put him to bed, within three days. People don't believe me 'cause other people tell me they waited, you know, years."

Sheila's repetition of "I cannot cope" emphasizes the drama of the situation and the fact that she had reached her limit as to the care that she could provide to her father. For Sheila this was not a voluntary withdrawal of care. Although she did not leave her father alone in the house she did manage to have a care package put in place in a matter of weeks. In her narrative, Sheila exercises resistance to the power of social services. As this was a service that was only contactable by telephone she approached the only other service where she could insist on being helped. The difficulty that Sheila has in dealing with her father's incontinence is likely to be more than a disgust of the excrement, although that would certainly be an important aspect. Bowlby et al. (2010) observe that there may be a clash of cultural conventions when a daughter has to bathe her father.

The conventions that surround the appropriateness of nudity in front of others are not restricted to filial relationships. Although culturally acceptable in current intimate relationships there are aspects of relationships that are not acceptable to those whose relationships began decades ago. Although Andy and Maggie had been married for many years, Sue described the difficulty with getting her mother showered or bathed and her father's reluctance to share a shower with his wife:

“the main problem they have at the moment Mum fell out of the bath one day and then refused to go anywhere near it ... so they had the bath taken out and a double walk in shower with a seat and handrails and everything put in, hoping that that would be easier than a bath. But Mum gets very confused and I said to Dad I think it would be far easier if you just got in the shower with her but for some reason he's reluctant to do that so I'm now trying to persuade him to get somebody in to help her but he thinks that she would be too embarrassed and I'm not entirely sure because she's forgotten after an hour. I popped in this morning and said you know 'how was your shower?' and she can't remember so I hear from him.”

Andy's discomfort in the idea of getting into the shower with his wife in order to wash her links to Jamieson's (1998) analysis of the changing meanings of caring. Jamieson (1998:9-10) analysed changing patterns of physical expressions of love and care over the last century and found that the ways in which emotional bonds were expressed were different ways to those accepted today. For example, expressions of emotion through physical affection have become more evident in recent years as family members dilute what is termed the 'stiff upper lip' approach to familial relationships, and now openly hug or kiss each other in ways that were considered to be inappropriate even thirty years ago. This seems to present a barrier for Andy and a reluctance to accept his daughter's suggestion that he take a shower with his wife. Perhaps he feels that this would bring an element of their intimate relationship into the public arena. In contrast to this, Sue mentioned that her mother was incontinent and did need to use incontinence pads which sometimes her father would ask Sue to buy. Sue was not involved in this aspect of her mother's care beyond the purchase of the pads and contrary to Andy's apparent discomfort with the idea of showering with his wife, he did not appear to be uncomfortable with caring for her toileting needs. This is perhaps because this could only be perceived as a task of care whereas showering together could be viewed as a sensual act which would not be appropriate to discuss publicly.

Bowlby et al. (2010:65) suggest that there is a reluctance to move to more formal care support that stems from the belief that 'normality' and personal identity can best be preserved through maintaining family care. There is a tension between this reluctance and the difficulties

that emerge when family and friends attempt to care for those becoming increasingly frail or requiring more and more specialist support (Bowlby et al., 2010:65).

The narratives in this section provide insights into the private world of care and how this can place huge strains on informal carers. Informal carers will continue to carry out their care roles even when this is having an impact on their own health. The participants describe how it often takes a crisis situation for both the carer and the care recipient to accept that formal care is needed. In these crisis situations it is unlikely that the care recipient will be willing and interested in becoming involved in situations that will involve the public discussion of their incontinence. Care choices are likely to be made by family members who are no longer able to cope alone.

Discussion

The narratives in this chapter have shown how caring relationships within families can evolve over time. They fit with the concept of 'caringscapes' proposed by Bowlby et al. (2010) which portrays care as a journey, suggesting a metaphor of a changing landscape with an uncertain path ahead. This discussion develops the idea of the journey by exploring further the peaks and valleys in the terrain, reflecting the way care needs increase and decrease. Regarding care needs as undulating highlights the fact that there is no point in the life course when we have no need for care, even if that is taking care of ourselves. As care needs increase there may be a gentle incline or a difficult uphill struggle; at the peak of the hill our need for care becomes more visible. For older people who experience a short illness the first need for additional support could be viewed as the first 'bump in the road'.

The chapter has examined the way in which families deal with the growing needs of older relatives. The provision of informal care often begins with family members increasing the amount of support they provide. This care role is negotiated within families and, in line with the findings of Finch and Mason (1993), these negotiations vary between individuals rather than being constrained by any unwritten rules relating to relationship status. Each negotiation begins with an acknowledgement that proximity is an important factor, particularly when hands-on care is required (Phillips, 2007:112), to be able to help they need to be local and available. Where more than one family member is living nearby, negotiations about who will or will not do the extra work hinge on an individual having a 'legitimate excuse', a reason not to provide care which is accepted as legitimate by the care recipient, rather than by any other family member. It was evident that some participants understood that these that 'excuses'

relating to being 'unable to care' rather than 'unwilling to care' were more readily accepted. However, there are situations where a family member may openly assert that they are unwilling to care, as in Sheila's case, where the relationship between the person in need of care and the person that is expected to provide care has a difficult history.

As feminist researchers have importantly pointed out, this thesis also was attuned to how gendered stereotypes shape the view of women as 'natural' carers, and how this plays in to caring relationships across the lifecourse (Larkin & Milne, 2014:30). For instance, Sue, was expected, and was willing, to support her father in the care of her mother, despite the fact that her brother also lived locally. In considering their employment status, Sue was in a far more vulnerable position as she was self-employed and any time taken to care for her parents would mean a loss of earnings whereas her brother would, presumably, have some paid holiday leave during which time he could have shared the care role.

A brief comparison of negotiations within traditional families, a man and a woman living with their children and those within non-traditional families, such as same sex parents or remarried parents with step children, indicates that the age of the relationship can be a factor in care negotiations. A relatively short relationship, particularly between new partners and children from previous relationships, may make a significant difference to communication when negotiating care responsibilities.

The narratives showed that not only were the family situations of the informal carers different but care needs of the older people also varied. For some there was a gradual, almost imperceptible, transition from independence to a need for support and the nature of the help that is given in these circumstances, visiting a bit more often and helping with chores, means that it can be offered and accepted without any explicit discussion. The relative of the older person becomes more and more entwined in their life and more aware of the capabilities, their needs and their preferences. This gentle change is not always the case, for some the change happens due to a sudden illness or an accident but for the participants in this study there was time to adapt to the changes.

Despite understanding that the older person was in need of support, there was little recognition by either the older person or their family that the tasks being undertaken were specifically care tasks. Participants spoke about 'helping' others rather than 'caring' for them, even when undertaking tasks which would be identified as care work if undertaken by a formal care worker, tasks such as lifting someone off the commode or helping them to brush their

teeth. As Larkin and Milne (2014:27) point out, the label of 'carer' is not recognised by many of those who actually do caregiving, Sue made a point of saying that she was not involved in the care of her mother, even though she did mention helping her mother to brush her teeth. The contested concept of the carer can be seen clearly through these narratives.

There are limits to informal care; in the narratives presented here, these limits appear to relate to being unable to provide adequate care rather than be unwilling to continue the care role. The stories surrounding incontinence provide insights into the private world of care and how this can place huge strains on informal carers. The transition of toileting from a private to a more public action seems to open the door to formal care services. Twigg (1999:392) points out that different parts of the body have different degrees of privacy attached to them, in particular the genitals are usually off limits. The narratives highlight how the willingness and ease with which informal carers are able to manage incontinence varies and may depend on the relationship between the care giver and the older person. Sue mentioned that her mother was incontinent and did need to use incontinence pads which sometimes her father would ask Sue to buy. Sue was not involved in this aspect of her mother's care beyond the purchase of the pads; contrary to Andy's apparent discomfort with the idea of showering with his wife, he did not appear to be uncomfortable with caring for her toileting needs. This is perhaps because the assistance with toileting would be defined as a task of care whereas showering together could be viewed as a sensual act which would not be appropriate to discuss publicly. For daughters and fathers the issue of toileting can be particularly difficult and in Sheila's narrative she explained that she could not cope with caring for her father when he was no longer able to use the toilet alone. The narratives suggest that spouses can undertake intimate tasks for their significant others but daughters and fathers find it much more difficult.

The method of dialogical narrative analysis involves asking questions of the narratives. In the narratives around family care, the questions of who is holding their own within the narrative and, in contrast, who is shown as vulnerable have provided a way of seeing how the care givers position themselves. Jerry positions himself as someone who is holding his own. Rather than showing his mother as the vulnerable individual he is showing his brother as less able to deal with their mother's situation. By exploring the narrative in this way, we can identify individuals who are undertaking a care role even though they do not describe themselves in this way. This was the case with Sue who explained how her brother did not seem to be able to cope with their parents care needs.

These stories of informal care describe how family members adopt the responsibilities of informal care and demonstrate the flexibility of the solutions found by the relatives of the older people, such as increasing visits, helping out when needed but not taking over. These descriptions fit with Mol's (2008) logic of care where small adjustments to daily activities allow care to be adapted to the needs of the individual.

Through exploring how older people, their families and significant others understand care in later life, the discussion here shows that the initial need for care or the 'first bump in the road' is described as 'helping' rather than 'caring for' the older person. The narratives portray a responsive care that allowed for relationships to adapt and change as the needs of the older person changed. The changes that are made could be considered to be the choice of the care recipients yet the language of choice is not one that is used by the participants in the context of informal care. References to choice appear when the care moves to the formal arena, notably those by June who said she felt that she had no choice but to let her husband be taken to hospital. Having observed the impact of the initial need for care, the following chapter picks up on the changes that the introduction of formal care brings to care recipients, their families and their significant others.

Chapter Five: Negotiating Formal Care: “She’s got to go somewhere because we can’t carry on.”

Introduction

This chapter explores three specific aspects of the participants’ experience of formal care: ‘choosing’ formal care; the shared experience of formal care; and interactions with care professionals. The move to formal care can arise as a result of a crisis situation or it may have been planned in light of increasing care needs. Discussions between older people and their families regarding formal care arrangements are necessarily explicit as opposed to the implicit evolution of care in informal care. First, this chapter explores the elements that participants describe when making arrangements for formal care; these include finding information about local services and considering which type of care would be most suitable for the older person. It is here that, in theory, the personalisation agenda would be most visible. However, rather than the older person actively considering the ‘options’, several participants describe making choices on behalf of a relative who was either not well enough to make decisions about their care or who trusted their relative to make the decision on their behalf. In exploring the decisions, the health care decision making models are considered and their utility in the context of social care is explored.

The narratives describing the introduction of formal care into the home where spouses care for each other emphasise that, for many older couples, care is a shared relationship even when one partner does not have care needs but does need help to provide care. For some participants this was regarded as an intrusion but for another it was an opportunity to continue the manageable aspects of caring and to ensure that the formal care was delivered so that the care recipient felt as comfortable as possible. This section also includes narratives describing how relationships with formal carers are managed and developed since these relationships impact on the care recipients’ perception of the quality of care given.

The chapter concludes with a section exploring interactions with care professionals. Once again the personalisation agenda leads one to anticipate professionals seeking to provide person-centred care. In the participants’ narratives, social workers are shown to be critical of the care provided by family. The difficulty of challenging poor care was described by carers who were keen to report failures but who were prevented by their own concern, or the concerns of the care recipient, about the consequences of such complaints. Care recipients

felt that they were not given proper care by doctors who sought to treat specific illnesses rather than considering the 'whole person.'

The chapter begins where the last chapter finished, the move to formal care when informal care breaks down. It explores the ways in which participants discuss the 'choosing' of formal care and considers the extent to which the experience of arranging formal care fits with the 'choice' narrative of social care policy. The narratives presented here show how the boundaries between informal and formal care are fluid with family members and significant others continuing to carry out particular tasks. The chapter concludes with narratives that indicate concerns over the funding of formal care and the uncertainty of future arrangements.

'Choosing' Formal Care

The decision to introduce formal care is not easy in either emotional or practical terms. The narratives in this section highlight the issues set out in academic literature regarding the difficulty in obtaining information about formal care services. They also describe the various aspects that need to be considered depending upon the situation and the preferences of the care recipient. None of these situations are 'crisis points' indicating a clear-cut need for care but the narratives of relatives show they are aware that formal care will need to be considered in the not so distant future.

Brendan had been suffering from deteriorating health, diabetes, arthritis and asbestosis. He was retired and although he had been active in local government his activities were now severely restricted by his health. He had difficulty in walking and was aware that he would benefit from having a Blue Badge to allow him to park in disabled spaces but did not know how to access information about appropriate services. His situation was very much as described by Baxter and Glendinning (2011) where he found out about services through a chance conversation with someone who had already been through a similar experience:

"Suddenly I felt very much alone, not sure where to go, who to contact next, who to speak to, looked on the internet and I have to say there wasn't a great deal that I found on there, on the government websites they seem to major on a lack of entitlement to anything and some very torturous and difficult routes to go to obtain any form of assistance and almost a brick wall unless you were already on some form government benefit. Then I think it was my brother said to me, I spoke to Age Concern he said about my father-in-law and they were very helpful."

Brendan described how difficult it was to get the information about blue badges without guidance:

“If you look on the internet about becoming registered disabled there is no route. Well I couldn’t find one, there is just no route, because I’ve been told for example if you have to use a motor vehicle because of your disablement then you are entitled to some reductions in all sorts of stuff, you know, vehicle excise licence and so on.”

Brendan emphasised the importance of being guided towards appropriate information:

“Oh absolutely, one needs supports, yes one needs support from people as you and I are talking now, but it needs to be in the form of tangible potential solutions. The sort of response of look on the internet, just doesn’t do any good at all, to anybody. I believe that organisations like Age Concern, or Age UK as they are called now, need to be better publicised, they’ve certainly got the knowledge, they’ve certainly got the expertise, I mean just one bloody phone call, that’s all it was and a new world was opened to me. The, there may be things available that I still don’t know about, lots of things.”

Although Brendan was looking for public services to assist him, he was also supported by his wife. Spouses also became carers for the other married participants; however, as the spouses age and their own care needs increase other family members may be called in to help. For instance, Sue did not want to put her parents into a care home but questioned whether she would be able to offer an appropriate level of care:

“I know Mum and Dad would hate that, absolutely hate it so, so I am kind of mentally prepared to move in even if Dad can’t afford to pay me, we will kind of work it out, sell the house, whatever, rather than put either of them in a care home but then people keep saying to me, yes but, you are not a professional and they might be better off with professional care. So it’s it’s difficult
I -Yes, it’s a big sacrifice as well isn’t it to...
Um well yes and no I think in terms of the guilt, I think I sort of would rather, yeah, kind of put my life on hold for a bit too, so that I knew that I’d done everything for them because if I put them in a home and they both end up as cabbages that would be horrendous.”

In this narrative, Sue appears conflicted between the level of care that she is able to provide and the guilt that she would feel in placing her parents in a care home. The language that participants use in relation to care homes is often that of ‘being placed in care’ rather than something that people decide for themselves and as such it is very different to the discourse of policy where choice is something that is meant to be undertaken by an individual after careful consideration of possible options. In order to be able to consider the choices that were available, Sue had started to collect information about local services:

“So it’s almost like things happen and you have to make the decisions but it’s the scurrying around trying to get the information because if you’re going to make a decision you want as much information as possible. You want to know what your options are and that’s what two years ago I found really difficult. Age UK were brilliant as a source of information and online the Alzheimer’s society were quite good as well

but social services, they came out and that's right, they were supposed to leave this big pack of information but she forgot to bring it with her so she posted it to Dad and it's like it's too much information."

This resonates with Hanoch and Rice's (2006:43) assertion that the more information older people have, the less likely they are to use it, although the nature of the information may have also been problematic for Andy. Another participant had provided me with a book that listed the care homes within Hampshire giving geographical information and details of size and services but no indication of quality. Andy spoke about the difficulty in getting useful information on the quality of care companies:

"And there are so many care agencies about the place that, which one do you pick and how do you know what they're like. My most recent experience and I think I have probably worked out my way round it. I'm no great shakes at ironing, I used to do a lot of it when I was soldiering but, shirts and blouses and things, the materials now are a bit more demanding than they used to be and we've got half a dozen shirts and tops to iron in a week. Now we get by, we manage it slowly, Maggie's back gets quite painful after a while doing it, even though she sits down. I finish it off and do my whack so I wondered if there was somebody who did ironing and I've been hunting around, I went to Age Concern and their Information Centre and their response was no we don't have any and we can't recommend individuals but we'll send you a list of care agencies and you ask them I am sure one of them will do ironing. I could hunt around I suppose but I suddenly thought well there's a perfectly good laundry in Eastney so I'm going to give them a ring and say hey do you collect even on a small scale? And you could launder and iron and that would be a help. So I will do that for myself."

Andy describes seeking information on services that are not directly related to personal care but that will support him in caring for Maggie. As Andy was suffering from his own health problems he was keen to show that he was still able to go out and find information that was pertinent to his needs. Sue's suggestion that Andy was not willing to deal with the wealth of information left by the social worker was perhaps to do with resistance to the idea of accepting formal care. Here Andy appears to be able to actively seek information that he needs regarding services but finds the nature of the information inadequate, he would like to know about the quality of services and he also wants services that will support him in household tasks and give him time to care for his wife. As Mol (2008) points out, the 'logic of choice' leads to the need to delineate the care that is on offer in a particular package available for the consumer to choose, this care 'product' needs to specify what is on offer and what is not. Whereas in the 'logic of care', care is a matter of various hands working together towards a result; the important element being time rather than a product that changes hands (Mol, 2008:21). For Andy, a logic of care would provide him with support to care for Maggie rather than a specific product that would deal with one aspect of one care task.

Heather had arranged care for her mother who was suffering an infection after having a plate fitted in a broken leg as well as being in the early stages of Alzheimer's disease. Heather was self-employed but also had a lot of expertise in managing people; this was mentioned in the conversation but was also evident from her management of the care staff that she employed. Heather had researched the type of care that she wanted and chose a specific agency based on a method of dementia care:

"...when they [the hospital] would no longer have her beyond the seven or eight weeks it was do I bring her home with permanent live in care or do we find an alternate? So I found Greenfields which is a local care home with nursing facility that took her in for another eight/ten weeks and then, obviously I had the lead in time to pay for and sort out the private full-time live-in care. With hindsight I would have not sent her to the care home just because it wasn't particularly appropriate for her, you know, there were people there with significantly bigger problems and it was just another unfamiliar environment which didn't help the dementia. But that's hindsight, you know, this time when she comes back out of hospital again and they say that she can go home as long as she's got care, she's going to go home and get care. In terms of the care, the care home, it was touch and go, is there a space? Isn't there a space? So you're living on tenterhooks sort of, at the same token being told but she's got to leave where we are now and organising the live-in carers I just have gone and paid the money through an agency. So you pay horrendous amounts of money, of which the carers probably get less than half but at least they've all been, the company I've used is called Hedley and the reason I chose them is that they specialise in the Speckle System or methodology of handling dementia ... I then went online to have a look at which care providers work with that system because it seemed appropriate to me. They specialise in it so at least all the guys that come through them have been vetted, have been checked and have been trained in that system, having said that we are now on our fourth carer. We're on a two week on, two week off rotation but we are on our fourth carer ... that's me saying for one of them the relationship doesn't seem to be working any longer. This is a lass that started, started out with her and did some long stints but culturally, she was from Portugal and culturally it just wasn't going to work. Quite loud, quite young and my Mother needed more of a companion that she did a housekeeper erm and one of the other ladies that came, I found quite challenging to work with because it was "yes, I can do it, I'm fine, it's all about me and it's all alright, it's wonderful" but actually it wasn't wonderful, it wasn't all alright and she actually wasn't coping and every time I tried to ask and help and support I wasn't getting the truth from her."

Heather's narrative exemplifies the uncertainty surrounding older people's discharge from hospital after an illness or accident. Because of her mother's health problems, namely the recovery from an operation, Heather had enough time to research the type of care that she felt would be best for her mother. Given the level of pain her mother was experiencing it appears likely that she would prefer that her daughter take over the care choices on her behalf. Heather had spoken about a time, years before, when she cared for her mother after a serious car accident. Heather said that she and her mother 'were a good team.' This

emphasizes Heather's understanding of her mother's needs as well as her mother's acceptance of Heather's role in arranging her care. Heather has appeared to take control of all the care decisions but the reference to them being a 'good team' suggests that these decisions could be viewed as shared decision making (in health care terms) as Heather is aware of, and takes into account, her mother's preferences regarding lifestyle and where she would prefer to be cared for and which carers she is most comfortable with. Also, even though Heather is not undertaking the care herself, she still views her mother's care as something that they coordinate as a team.

Another participant who described having enough time to research local care choices was Barbara. Barbara was aware of her mother's failing health and had selected a care home without her mother's knowledge. When her mother's health took a turn for the worse after a heart attack she was aware that she could no longer live alone and Barbara was able to avoid a crisis situation:

"My mother had....I knew her attitude, um, she didn't want to have to go, obviously, and, um, she had a big heart attack the phone rang, we didn't hear it, our daughter was still living at home she came up to us and said 'its' either a silly phone call or its Grandma' because she could hear (heavy breathing) so I went round and she was having a heart attack,

I've had quite a lot of experience in a way, of people having to go into care because my mother had to eventually because she lived next door and we kept her going in her own home for a long time and the doctor had said that in nine months she would not be able to manage so I started looking. Well we weren't in a crisis position and then she got to the point when she said 'you're not going to manage' and I said 'well I have looked at one or two places' and we took her somewhere, she needed to have furniture she could touch so couldn't be somewhere she could, you know, walk across a big room and all sorts of things happened, and we found somewhere. So we looked around, somebody had recommended somewhere and I went to look at it, and it had pop music playing, so I didn't even go in just said 'thank you very much' and came out again because I knew that wouldn't suit her. Luckily just nearby there was a care home, went there and just asked if we could look, it was beautiful, it was like a hotel, it had been a hotel so we explained the situation and they let us have a look and luckily when she did need care they could take her."

For Jerry's family the move from informal care in their home to formal care in a nursing home was another example of a decision that was made in advance of a crisis. Things had gradually changed but because of Jerry's experience with his parents-in-law he knew that at some point he and his wife would no longer be able to cope:

"Well my brother and I looked at another nursing, looked at places where she might go and we had several recommended to us and we went and had a look at this one and we liked it ... It's very quiet, it's surrounded by fields, it's not the cheapest but it's

quite relaxed and it is a friendly kind of place and I don't think you could do much better in a way ... it's not a big place but big enough. I don't think she would like to be in a bigger place than that really."

Having selected the nursing home without any input from their mother, Jerry described how they had to tell her that she was going to be moving:

"Well the traumatic bit was telling Mum 'you can't live there anymore you've got to go and live in a home' and that worried me quite a lot beforehand and we got the doctor in, just for that event. He came to look at her knees and see how they were but I had arranged with him beforehand that please would you come so that we can tell her that we've got a nice place fixed up for her and that she's going to have to move down there. So that, for me, that was the traumatic bit, the bit beforehand I suppose the most painful bit of the experience. I mean realising that we couldn't carry on the way we were was, well that just became obvious really and actually the, having a, there was a concrete line there, I think Beryl realised that from her parents that you can actually describe ahead of time what, there comes a point, what the point is. With Mum it was her knees, once she couldn't stand up we thought that's it she can't stay here, you know, there's no point in trying to carry on because we weren't going to be able to manage, just physically we can't manage, that's when she's got to go somewhere because we can't carry on."

Jerry and his wife had set a clear limit to the level of informal care that they were able to give and this was related to the physical aspects of personal care and the difficulties arising from Jerry's mother losing her ability to stand unaided for even a few moments. Although Jerry presents the decision as a logical and reasonable decision, it appears that he is uncertain that his mother will view the decision in the same way and so he asked for support from the doctor when first discussing the move with his mother. The doctor's presence suggested a medical foundation for the move. Drawing on the health care decision making models this could be viewed as a paternalistic decision made by Jerry, his wife and his brother without any explicit discussion of their mother's preferences (Charles et al. 1997:683). However, Jerry and his brother selected a home where they instinctively felt that she would be comfortable. The home was close enough for Jerry to be able to cycle to visit and for his brother to drive to easily. Presenting the idea of the move with the doctor present was a way of reducing his mother's scope for resistance. Although she had not been involved in the selection of the home, and the presentation of a *fait accompli* might have been upsetting, the brothers appear to have been trying to avoid stressing their mother until everything was arranged and in this way they were seeking to provide good care by finding information about care homes, doing the visits and taking the final choice together as brothers. This is an example of the non-physical but challenging aspect of care where sometimes care is about "making moral judgements about the best thing to do in difficult circumstances" (Barnes 2012:18). Jerry and

his brother judged that the move to the care home would prevent harm being caused to their mother as Jerry could no longer provide the level of care that she would need.

The narratives also show the difficulty in accessing information, particularly in the case of the quality of care homes. The stories in this section illustrate the differences between making choices in preparation for future care needs and making choices in crisis situations, as shown at the end of the previous chapter. Although these narratives illustrate that there was sufficient time to collate information and deliberate on the options available there was a definite sense that this was preparation undertaken solely by the relative and the older person was not involved in the process at all. This was not an attempt to disempower the older person but appears more to be a continuation of the act of caring, relieving the older person of the burden of having to contemplate a future of increasing dependency. These stories show that the decision to put formal care arrangements in place vary widely between families and the timing of them depends on the rate at which the older person's care needs change.

Shared Experiences of Formal Care

Tronto (1993), Barnes (2012) and others emphasise that care is about relationships and that it is a shared experience. Exploring situations where a spouse is caring for their husband or wife highlights that the tasks of informal care are not only part of the shared life experiences but the introduction of formal care is something that impacts on the life of the carer as well as the care recipient. For some participants the introduction of formal care was difficult to accept.

One participant suggested that this difficulty begins with a reluctance to accept the physical changes of age. Stephen describes the difficulties his parents faced:

“They found it very difficult to accept the loss of abilities that they were experiencing and the loss of control over their world and very uncomfortable with the idea that they should give up their home, should give up the independence they had and it came to a head with illnesses and falls ... what strikes me is that we all take the decisions much too late. You know, my parents were deteriorating and you have to make good sensible decisions before you deteriorate and then because they are not deteriorating they are not making the decisions and by the time they get round to making the decisions they are no longer even capable of it.”

Where an older person is caring for their spouse, the burden of care may have an impact on the health and well-being of them both. The carer may be reluctant to give up their caring duties and may resist attempts by their family to introduce formal carers into the home.

Penny described how her grandmother was struggling with the physical demands of caring for

her husband who had Parkinson's disease. Although it was difficult for the family to broach the subject, formal carers were organised to visit several times a day:

"...it's like it was her duty, you know what I mean, it's very difficult because it's kind of seen as her, and she sees it as her duty as well and as her position. This is why we found it so difficult to, kind of, infiltrate this, this power, this giving up the control thing. My Nan's, you know, quite sociable and she'd give them a cup of tea and a biscuit and all that stuff. But the other thing about it was, this was what really annoyed me was, because my Nan doesn't want to relinquish this control she was almost doing everything before the carers got there. So she'd done everything, and they wouldn't come in and say, what have you done that for? You know, not in a nasty way but that's our job, you know, my Nan needs to be told that's our job, you're not allowed to do that, but they loved it and in fact when I looked at, because they haven't got those carers anymore, when I looked at the care plan, it made me very angry because I looked at all their entries because obviously they do one every time they visit. Mrs Cole helped lift Mr Cole, you know, Mrs Cole assisted with changing pad, Mrs Cole assisted and I just thought what the hell has been going on here. You know she's 80 odd."

Whilst Mrs Cole's relatives were seeking to provide her with support, she was reluctant to give up her role as carer. Hoggett's (2001) model of non-rational agency can be used to explain Mrs Cole's insistence on continuing to undertake care tasks despite the presence of formal carers. On Hoggett's (2001: 47) continuum of agency, Mrs Cole's actions lie toward the non-reflexive end where Mrs Cole may feel dominated by those around her who are insisting on the change in arrangements. Her actions are impulsive, as in not planned or contrived, and may not result in a positive outcome as she continues to jeopardise her own health. Mrs Cole is powerless to stop the intrusion of formal care into her home and resists by acting as a host to the people who visit her home. In this way she can hold on to the role of caring wife.

Sue encountered a similar difficulty when she arranged formal carers to help her father after he had a knee operation. Her father was the main carer for her mother suffering from Alzheimer's:

"... he was finding it so difficult to move I suggested that we get carers in to get both of them used to people going in really, in the expectation that when he came out of hospital he would need some additional help until he got back to normal. So we went to a care company in Westfield because they were recommended by somebody who'd used them and found them quite good so they came in and did an assessment on Mum and they came in for 15 minutes a day. Just to kind of check up on them and see what needed doing really and as I say I was trying to get Mum and Dad used to the idea of somebody going in. Dad's fiercely independent so it got to the stage where they were just rocking up and not doing anything cos Dad wasn't kind of leaving anything for them to do. So that lasted probably only a month or two. It kind of fizzled out."

Andy was able to put forward his view of the arrival of carers in his home:

“At the time when we had the carer fairly early on, there wasn’t so much for them to do so they come in and chat and that was it. A quarter of an hour and they were off and that was just a waste of money.

I – That wasn’t adult services arranged that

No we arranged that ourselves. Adult services haven’t arranged any caring for us at all and I’m not sure that I would want them to. Just because I am an independent and grunty old so and so.”

In a similar way to Mrs Cole, Andy was resisting the intrusion into his home. In Andy’s case we can see that the risk to his own health of undertaking physical tasks whilst recovering from an operation could impact on his daughter and be detrimental to her well-being if she has to step in and take over care. This links to Hoggett’s (2001:38) assertion that there are forms of agency that can be destructive both to self and other. This form of agency calls into question the extent to which choice is appropriate in informal care relationships. It is not possible to isolate the choice so that it has no impact on informal carers.

Sue explained her concerns about the impact on her life if her father is unable to care for her mother and is in need of care himself:

“So he was kind of struggling with that today but then maybe it is good for them to still do what they can but I’m terribly aware that they’re quite precarious at the moment and the other difficult thing is you can’t really put anything in place until you know what they need but talking to friends it seems to be that usually they leave asking for help too late and then one of them has an accident and ends up in hospital and that’s when everything changes drastically and I’ve told Dad this, I mean we have some fairly frank discussions and I said you know I don’t want that to happen I want you to have what support we can get in for you so you don’t end up in hospital.”

Her father Andy described how he felt about the formal carers:

“Now it’s just, it’s getting ready in the morning, up and showered and dressed, getting Maggie up and dressed and I just feel it would be an intrusion in our life to get anybody else to do that when I can do it. Fair enough if I fall over or can’t then I think Sue would take over but I just feel I wouldn’t like a stranger, maybe it wouldn’t be a stranger for long, a stranger coming in and doing that. Which is probably wrong of me but that’s just the way I feel.”

It is possible that Andy feels that he is protecting Maggie by undertaking the care for her himself. As has been discussed earlier, the dirty work of caring for an incontinent spouse appears to be more acceptable than in less intimate relationships. Whilst Andy is taking positive actions of ensuring that the chores are completed before the care workers arrive he does not directly confront Sue with his refusal to accept care. This approach might be regarded as ‘passive resistance’ in that an individual acts in a manner that bypasses direct confrontation but, nevertheless, continues to act in a manner that achieves desired outcomes

(Lorentzen, 2008:74)). Although this resistance is described as passive it is still very effective and can be regarded as a form of agency. Deacon and Mann (1999:413) define agency in terms of actions, decisions, and behaviours 'that represent some measure of meaningful choice'. Hoggett (2001:52) argues that there are problems with this definition as it excludes non-reflexive action from the category of 'agency'. We may act impulsively/involuntarily and be surprised by our own actions (as if it is an unfamiliar, split-off person but still part of me that acts). A second difficulty with this concept of meaningful choice is the suggestion that there is a freely choosing individual actor who is somehow disembedded from the social relations and networks in which they are immersed (Hoggett 2001:52). In Andy's situation he believes that he can continue to care for his wife and that if he should fall over then his daughter would be able to step in and continue the care for the couple. His daughter Sue had mentioned that she was not financially able to take on full time care for her parents. If Andy was no longer able to care then he would have to accept formal carers within his home and at the same time his daughter Sue would be required to make the arrangements and put things in place in a crisis situation rather than as a preventative measure.

The participants in the preceding narratives had difficulty in adjusting to formal carers coming in to their home. While Andy and Mrs Cole resisted, this was not the case for all participants. June found ways to adapt and used the formal carers to support her own care work, she managed their tasks. June arranged for a care company to provide carers for her husband who was unable to get out of bed and needed help with washing. June had strong opinions regarding the age of carers, these ideas stemmed from her experience with two carers in particular:

"I did have two older ladies in the morning and that was lovely because my husband didn't like these young girls washing him. He was 91 he didn't mind the older ladies, and I can understand that, you know, and they didn't have the sensitivity that the older people had. Like the older ladies that came in the morning they would cover, because he didn't wear pants because he'd got the catheter, they'd cover his bits with a little guest towel, you know it was just experience really wasn't it really? There was nothing wrong with the young girls but they were very young and inexperienced and they were always very sweet but they needed a bit more guidance sometimes ... but I was pleased with my older ladies in the morning. I think it's important when you're elderly you do not, particularly if you're a man, you do not want young girls doing things. They look like his grandchildren, and there's all my granddaughters up there, they look, you know (Yes – you don't want your grandchildren doing that) Well that's what they looked like, these youngsters that came in at tea-time."

June made the point that she did not overtly show any preference to the older care workers and was careful to ensure that she was on good terms with all the care workers but that she did allocate particular jobs to her preferred older carers:

“I didn’t want to make bad relationships or anything, did my best to make them welcome, I always offered them drinks and what not but they were always in a rush. That was the thing, they were always in a rush to get to the next place but they always did what I asked but I wasn’t very demanding (yeah) you know they did what I asked, if I said I wanted his pyjama top changed or whatever, I would put it out before they came in the morning. I all, actually I think I put on these two ladies in the morning because they were so good at doing things.”

June accepted that her husband would be better cared for with the formal carers supplementing her caring. Her awareness of her husband’s preferences and her ability to manage the care tasks that were assigned to the formal carers meant that she was able to ensure that her husband received person-centred care that took his preferences into account.

Barbara also spoke about the age of carers for her friend:

“Some are very young some of them aren’t, and also Steven had somebody that he didn’t really, particularly get on with, you know, just no I don’t like her coming and he said could I not have that person, that’s fine, you know they took notice ... So they were flexible and no they didn’t just send young things who didn’t know anything, and towards the end of Steven’s life he had to have sort of personal things done for him, obviously.”

Twigg (2000:146) discusses the issue of the age of carers but puts forward the perspective of the care worker. In particular for younger care workers the sight of older bodies was a novel and, to some degree, shocking experience. Caring for ageing bodies means confronting one’s own ageing; while the younger workers joked about putting cream on their bodies to keep old age and its wrinkles away, the issue was for most of them a remote one. Ageing was a mystery, something that was hard to grasp and that did not, by and large, directly impact on their lives. For them the distance between the ageing bodies of their clients and their own bodies was too great to be able to make sense of (Twigg, 2000:146). Wolkowitz (2006:164) suggests that the way in which different care workers conceptualise bodies can be due to the “material experience of interacting with the bodies which form the site of work”, as such it may be that the younger carers are seeing June’s husband as a body to be worked on rather than a body that feels embarrassment when exposed. Older care workers in Twigg’s (2000) study identified more directly with the ageing process and its impact on their own bodies. Twigg (2000:147) suggests that older carers caring for older people “offered a glimpse into a personal future that was discouraging and unwelcome; and though they accepted it, many

chose to push such thoughts away". For June's husband's carers, it seems that this glimpse into the future enabled them to care in a manner that was perceived by June to be more empathetic than the care provided by the younger carers.

Joanne spoke of the age of her carers, not in terms of experience but more to emphasise that these carers were of a similar age to herself:

"So, again, people get so fed up with me saying this, but I'm just so lucky with my carers. I mean obviously I've had some pretty rotten ones but I've had one now for 14 years, she is cutting down, she is now 66, she is cutting down and so she only does two and a half days a week now and, because you know she's getting older and the grandchildren are growing up and she wants to spend time with them. Well fine. But I also have a friend that I used to teach with, I have two friends that I used to teach with who used to come and put me to bed, you know, completely untrained or unqualified and they put me to bed and so on or get me up. That's fine but I really don't feel that I can ask one of them to do the really personal work which, I don't like to ask her to wash my bum (yeah) but (coughs) the other one I could, that was fine. And unfortunately she died last year but it's most annoying of her because I had her all planned to do my funeral service and you know we discussed it and so on and she goes and beats me to it! Then I've got another lady that I advertised for in the shop down the road, (oh right) and that was just for a couple of weeks, more or less just to cover the other carer and the stuff that she was doing, and well she is 76 and my friend from school is 74 (right) and the 76 year old is absolutely fantastic, she will do anything, anytime and she lives just down the road (very handy) yes and she is lovely and we get on really well but she's 76!"

The above narratives link to Hochschild's (1983) concept of 'emotional labour' this term refers to the management of emotions and the presentation of appropriate emotions in particular situations. The older carers in June's narrative are viewed by June as more skilled in the management of their emotions and are able to undertake the care tasks with little to no display of the work that is involved. The subtle placing of the guest towel over the private parts while they washed June's husband is an example of successful emotional labour and skilled body work. It is understandable that a younger carer may not have the life experience to understand the importance of this labour but this is certainly an aspect that may be improved through training and an explanation of the impact that this intimate care has on the care recipient. It is also possible that as an older person looking back on their own life experience, the participants assume that younger workers will not be as able to cope with the demands of care and so they look for moments when the younger carer's emotional labour flounders. Joanne suggests that it was not necessarily a question of the age of the carer but rather some instinctive understanding of care and the ability to deal with the 'dirty work' of care:

“You do have to ask carers to do pretty revolting things you know, if you’ve lost complete control of your bowel, you know, it’s not much fun. I think I’ve never had a carer who did sort of purse their lips or anything. The normal way of finding somebody is by just saying to somebody have you ever thought of so and so. I mean I’ve done that with one of the kids who came here for extra help and I said to her mother oh, when the kid was virtually grown up I said have you ever thought of going into caring and she said well funnily enough it has crossed my mind but I’m not trained and I said well if you’re interested come and put me to bed and I’ll talk you through it and she did and then she went and qualified ... you know you spot somebody that you think has the time and the right sort of attitude and you can mention it to them.”

Ungerson (2005:196-201) describes different types of relationships between carers and care recipients and this concept of care relationships links to the possibility that they share the experience of care. Ungerson (2005) identified relationships that ranged from ‘cool’ relationships which were characterised by acceptance and respect on both sides of the relationship and ‘warm’ relationships where care users reported enjoying the company of their caregivers or workers and vice versa and appreciated the two-way flow of support that often arises in good care relationships. Such warmth often arose out of care relationships that had continued over a long period and the warmth itself meant that these relationships were not at risk of breaking down, at least in the short-term. Joanne spoke warmly of her carers but did describe another MS sufferer who appeared to have difficulty in retaining carers:

“There’s a lady in Sudbury who is always advertising for care and I pointed it out to several of my carers and said well if you wanted any more time, look she’s always, in fact she rang me up once. I don’t know how she got my number but she rang me up and said, you know, would any of your carers like to come to me as well and I thought well I’ll ask them but no, no you see, carers themselves have a sort of blacklist (right) that they won’t go to and I know that another teacher friend of mine. Well she wasn’t a friend she was an acquaintance who lived down the road, behind me, and Sue went to her, twice I think and I said well I’m surprised you didn’t go because she’s quite near. She said oh, oh no, oh no. I said what’s that, ears pricked up (laughs) really? And she said oh no, no no, if you finish what you are there for, if you finish it before the hours up she’ll have you picking the bits of fluff out of Velcro, you know where it sticks? She’ll have you picking them out with a needle (oh) rather than let you go early at all whereas, I mean once I’m up and in my chair, well please go because then I want to get on with my day ... so I mean this particular carer, I pay her for an hour and I doubt that she’s there for half an hour but she’s done everything at the rate of knots so, and they say, no she has to have this folded this way and that folded that way, no no undo it, shake it all out and fold it again, but you see it doesn’t pay, it doesn’t pay, ok yes, I would like things done differently. I’ve got my quirks about things just as everybody else has. I mean, I’m trying to think of them, (laughs) yes I have the curtains is one of them (the curtains?) yeah I like them being straight and just dragging them back and hooking them up, no. But if you are going to be awkward, if you are going to greet them every morning with, God it looks foul out there, I don’t want to get up, you know nah nah nah nah. Then what incentive have they got to come? You might be feeling like death warmed up but you can’t let it show because otherwise they’re

going to be carrying you, mentally not physically and they won't want to come so a lot depends on the invalid themselves"

This narrative shows that emotional labour, hiding our own feelings of irritation or unhappiness is important for care recipients as well as care givers. In particular for Joanne who positions her carers as friends and values the personal relationship that she has built with them. Hochschild (1983:76) discusses the emotional labour that is involved in the exchange of gestures between people. She suggests that a giver and receiver share an expectation about how much sincerity is owed, gestures can be judged as paying less or more than what is owed. When the receiver of a favour responds less generously than expected, the giver might openly say, "So that's all the thanks I get?" (Hochschild, 1983:78). Alternatively, the giver may redefine the gift as a voluntary act of pleasure: "Oh no, there's nothing to thank me for." The sincerity of such a statement, and perhaps the effort needed to sustain it, is a gift in addition to the gift. It is the gift of not seeing the first gift as something to feel grateful for at all because that is just the kind of nice person the giver is (Hochschild, 1983:78). Hochschild (1983:82) suggests that we actually keep a mental ledger with 'owed' and 'received' columns for gratitude, love, anger, guilt, and other feelings and normally, we are unaware of this and it only when 'feeling rules' are broken that we become aware of what feelings are owed to another.

The exchange between people of equal status in a stable relationship is normally even, we pretend interest, or suppress frustration. However, when one person has higher status than another, it becomes acceptable to both parties for the 'bottom dog' to contribute more (Hochschild, 1983:84). The deferential behaviour of those in such a position, women for example, comes to seem normal, even part of a personality displayed through encouraging smiles, the attentive listening, the appreciative laughter (Hochschild, 1983:84).

'Inappropriate emotion' may be construed as a non-payment or mis-payment of what is due, an indication that we are not seeing things in the right light (Hochschild, 1983:83). By not allowing her carers to leave when their care tasks are completed, the lady in Sudbury is not showing the appropriate amount of emotional payment for their care, she is displaying inappropriate emotion. Whilst Joanne considers her relationship with her carers as a friendship there is still an element of inequality because Joanne relies on her carers to get her out of bed and washed and so on. It is perhaps because of this inequality that she feels that she should provide more in terms of emotional gestures or emotional gifts.

This section of narratives highlights the relational aspect of care. For older couples where formal care is introduced the experience of care is a shared experience as they both have to accommodate strangers coming into their home and becoming involved in their personal routines. For some this is particularly problematic but for others it is something that is managed to ensure the best care for the care recipient. The age and gender of carers is something that care recipients appear to want to be able to make choices about, however, this could be a difficult topic to approach with the carers themselves. Barbara's narrative suggested that some care companies are willing to make changes with regard to specific carers. Joanne who employed her carers directly also described the relationships with carers and suggested a need for the care recipient to undertake 'emotional labour' and appear as pleasant as possible so that the carers are happy in the relationship. Joanne also described how employing carers can become problematic if a care recipient gets a reputation for being difficult. These narratives describe the interaction with care workers within the care recipient's home. The following section explores interaction with care professionals such as social workers and doctors.

Interactions With Care Professionals

The attitudes of professionals both social workers and doctors was a matter that was discussed in depth by several participants. Three participants spoke about interactions with social workers. Penny's grandparents had two social workers involved in their care; the first social worker was removed from their case after Penny's mother made a formal complaint. Penny spoke about the first social worker that was involved in her grandparents' care:

"They already had a social worker in place but then the social worker who was less than effective. He was very new to the area, he didn't know really anything, he quite newly qualified I think and he just didn't know what he was doing. He was very confusing when he spoke to Nan and Granddad he didn't make a lot of sense because he kept jumping about all over the place. And also he didn't have any sort of empathy or any idea really, or any sort of, he didn't want to get a handle on their situation. He just sort of would look from the outside in, he wasn't particularly interested. "

Penny's step-father is a social worker and so her mother was confident that the level of service they were receiving was not appropriate. Having this prior knowledge mean that Penny was aware that there was an element of choice in the management of her grandparent's care and she was aware of where complaints should be addressed and how to go about having a new case worker appointed. The change in social worker led to a change in the company that was delivering the care through careworkers at Mr and Mrs Cole's home:

“So during the time Nan was in hospital we changed social workers, my Mum made a huge fuss, made a formal complaint about the social worker, he wasn’t doing enough, he wasn’t doing anything ... So then we got this new one who has been fantastic all the way through. She immediately upped the care package to four proper care visits a day, including meds in that. So they are not allowed to give meds but they can prompt meds ... So we met with this woman from the Care Company and she was amazing, she came up and she spoke to my Granddad and me and my Uncle Rob who was up there at the time and she was fab. She said even if there’s snow, we will get up here and we’ll, we’ve got a four by four and don’t you worry it’ll all be fine, you know etc. etc.”

In a similar way as Peel and Harding's (2013) participants described battling their way through the maze of services, Penny described finding arranging care as a fight:

“It’s just everything is such a fight all the time, such a fight, just to get anything done really between the social worker, the social worker was just unbelievable, when she was in hospital after her first heart attack she was then under the care of the hospital social work team which is different to the community social work team, ... We spent a huge amount of time, my Mum did, I did, liaising with hospital social, between hospital social worker and community social worker to get them to talk to each other about the various issues that were going on, they never really did so we had to do a huge amount of work in speaking to the hospital and making them aware of the whole situation, trying to get them to communicate with each other, letting them know what was going on. Usual thing we had it all set up for them to go and do an assessment on Nan to assess what her needs were and whether she could be taken to the care home or not, we had it all set up with the lady who was going to do [it], the assessment was then done on the Saturday when she was off. We had some absolute arsehole walk into her, up to her bed, bearing in mind she’s 86, she’s had a heart attack and say “Hello there Mrs Cole, ah you look alright don’t you? You do know you’re not going to get funded to go into the care home don’t you? I think you’re going to have to go home” and left.

... He obviously thinks he knows what he’s doing so, you know, what an arse. But you generally find this all the way along you come across these brick walls all the time, you have to explain and explain and explain over and over and over again and bang on doors and just get stuff done.”

The frustration that was felt by Penny demonstrates what an emotional experience the arranging of care can be. The description of brick walls contrasts with Bowlby et al.’s (2010:6) imagery; their discussion of a ‘well-trodden path’ and ‘an interesting byway’ suggests a rural landscape where there is a freedom to meander. Penny’s discussion of brick walls offers an image of an urban landscape where the route is more confined and restricted to pre-determined lines of travel. This more restricted, and confusing, view of care is also found in Peel and Harding's (2013) discussion of the ‘terrible maze’ of care. The restrictions to the care journey seem to be put in place by the care professionals that participants expected to be supportive but instead come across as uninterested and detached.

The reason for the distance between the expectations that the participants had of care professionals and their actual experience may relate to the emphasis that care professionals place on risk in contrast to the emphasis that the participants place on care. The social workers discourse of 'risk aversion' described by Biggs and Powell (2001) became evident in two narratives. This discourse shifted the role of social workers to that of risk-assessors who now reflect the political and moral concerns about the willingness of relatives to take up the transfer of responsibilities from state care to private care (Biggs & Powell 2001:15). In the narratives presented here the social workers were critical of the care that the family was providing or planning to provide. Heather's mother was due to leave a nursing home and Heather had arranged for her to have full time carers at home. There was no funding for a longer stay in a nursing home but Heather felt that she had to battle to care for her mother in the way that she and her mother felt was best:

"...we did get a social worker, she did come out, you know, but it was very much on the basis of we can't really let you take her home because she's not fit enough and if necessary we will fight you for that"

The combative nature of the relationship with social workers was echoed in other narratives. Sally's interaction with social services was also problematic:

"Also there was also whatever the mental deterioration was, and we never quite got to the bottom of to what extent it was dementia or to what extent it might have been a mental health issue. So she would go wandering around in the night, there was some drinking going on, noise, banging on neighbours doors at 3 o'clock in the morning and this sort of thing that got quite exciting. My brother would tend to go, be the one that would try and go up and sort it out because he is the one that had a better relationship with her and we had, she did manage to set the house on fire because she got candles and lots of stuff dangling round the porch and she put some candles there and she just thought that was hilarious. Then social services got involved but she's fine, you see, she's absolutely fine, what's the problem? Social services got involved and the thing that still rankles with me and I may yet one day complain about it is that I had this woman from social services having a go at me for the house being untidy. ... well I sort of tried to say to her well it's quite difficult to tell them what to do and she gave me a lecture on how she would never let her mother live like that and I went well, yeah alright it's worse than it was when I was growing up but do you know it's not that much different. I really had, felt like having this real childish tantrum of well where, where were you when various things were going on. Don't get me wrong I didn't have, I had a much more privileged than many people in this country, never mind all over the world, however, some of it was a bit crap and it's like, you didn't come round then did you? You didn't care then?"

These judgements from the social worker were particularly difficult for Sally as her brother was the main point of contact for her mother whereas Sally had little day to day contact. Sally's comments about her childhood suggested a difficult relationship whilst she was growing

up and this was clearly an emotional and upsetting subject for Sally. This links to Sheila's assertion that her earlier relationship with her parents had an influence on the future care that she provided. The social workers' comments were unnecessary and judgemental as she was assessing Sally's mother's needs but then judged that social services were not able to offer any support or a solution to the family's difficulties. This attitude by care professionals was echoed in other participants' narratives.

Other narratives also described the feeling that participants did not feel supported by health professionals. June spoke about her experience of managing her husband's diabetes:

"I did all his care, I had virtually no support from the community, he was put on insulin and as a result from one blood test and a very nice nurse Lynn came and called and showed me what to do and that was the end of it really. I never ever had a problem with the insulin, I always kept his blood sugar level ok, in fact I preferred doing the injections to having the tablets because when you do injections you can have the odd naughty because you can counteract it by a couple of extra units so if we've got the family here and he'd had some naughty pudding which, I could put in an extra couple of units and his blood sugar would be fine. So that was not a problem at all, it would have been nice if somebody called. I did have, I did complain, well nicely, at one time that nobody called and I did have a very nice district nurse called. I think she only came about twice or three times and she said oh you're doing alright and that was amen to it, you know (mmm). Doctors didn't check up, I didn't get, apart from twice yearly check I think we had that was all so I really was on my own."

Whilst commenting that she felt that she did not have support, June also positions herself as proficient in managing her husband's diabetes. The adjustment of insulin to accommodate his daily sugar intake shows her understanding of the nature of the care work needed to manage the disease but also positions herself as someone who is able to navigate the system and bend the rules.

The following narratives refer to concerns regarding the consequences of complaints. In cases where the family carer did not feel that their loved one was receiving the appropriate care they were keen to make a fuss and insist on action being taken, however, they were concerned that such action would have consequences of the future care of their relative. Heather spoke about trying to get someone to review her mother's case to work out why she continues to suffer pain. I asked her who she would approach for this review:

"The physio, the GP and the consultant I mean I've ended up, rightly or wrongly, cheekily, directly emailing her consultant after she had the break because he also works at the Southampton General although he wasn't able to do the break and in the end I've emailed him personally and said "Is there any chance that there's still an infection?" Not wanting to tell him how to do his job. So I'm cheeky and I have frank conversations with, they hate me at her practice I'm sure, her GP practice. I'm sure all

the district nurses hate me, I don't care. But you know there are some that are brilliant and there are some that they're clearly paying you lip service and you kind of go I think that feedback needs to go back but I daren't because I don't want them ultimately to take it out on her."

In a similar way to June, Heather positions herself as being able to manipulate the system to an extent by being "cheeky". Although she is positioning herself as resisting the power of the GP and the district nurse she could be regarded as conforming to the neoliberal imperative of entrepreneurialism as she creates her own lines of communication with the consultant (Lemke, 2001:202). From her previous comments regarding her work as a consultant she positions herself as having power and resources in other areas of her life that she can draw on when organising the care for her mother.

Sue also spoke of her reluctance to make a complaint because of concerns that it would be taken out on her father. In her case, however, it was her father who was concerned about making a fuss:

"After his bowel op he was supposed to be moved by two nurses and one day one bloke, one male nurse tried to move him and dropped him and so he landed on his knee that had only been done seven weeks before and they tried to pretend it hadn't happened and I was absolutely furious and spoke to a lot of people about that and tried to get the bloke disciplined but I don't think he was. But again Dad was worried Dad didn't want me to make a fuss because he felt quite vulnerable."

These narratives link to Harrison and Smith's (2004:376) assertion that trust and confidence are different and whilst a service user may be confident that a care professional possesses the essential knowledge and skills to do a competent job, they may not trust in their motivation to do a good rather than simply a competent job. Care recipients seek reassurance that care professionals are not only competent, but also care about their satisfaction and well-being (Harrison & Smith 2004:376).

This section has covered a wide range of experiences with care professionals. Narratives have shown little evidence of services being tailored to individual needs (Social Care Institute for Excellence, 2012). The older person does not appear to be empowered or in control of their care. In the narrative by Sally regarding the social workers criticism of Sally's mother's home it seems that Sally was the object of the assessment rather than her mother. Participants also described times where they wanted to make formal complaints because of problems with the care of their relative but they held back from making complaints because of their concerns that these would result in problems for their relative.

Uncertain Futures

The distinguishing feature of care for older people is that it is finite and there is no 'cure'. The closeness to death means that care is about preserving independence and ensuring that for the last years of life the older person feels that they are cared for and cared about. The uncertainty of the duration of care was discussed by Sue who spoke about the difficulty of the slow decline and of not knowing how long her parents will be able to cope:

“... the other thing that I'm finding difficult is not knowing how long it's going to last 'cause it's a couple of weeks ago I realised that I've just put my life is completely on hold already and you know wasn't making any plans because I didn't know if they would need me and I'm just kind of in limbo and I think this is just ridiculous because this could go on for years so but I need to sort of do stuff for me until I need to stop but there is no point in stopping now ... I feel, the decisions are ones that you have to make so something happens and then you have to decide what's the best thing to do, you can't plan.”

This uncertainty of duration leads to concerns over how care will be funded and what the nature of care will be in the future. The lack of definite duration of care means that an exact amount of funding for the future cannot be calculated and the concerns over future funding are significant. I began my conversation with Joanne with a question about funding and whether she had a personal budget or was self-funding:

“It used to be a personal, it used to be given to you, you had, in the good old days, about ten years ago I was paid £900 a month to pay for my carers (right) and any sort of extra help that I needed above my disability and Motability allowance and that £900, I mean obviously it was tailored looking at my expenses and how much the carers cost and so on and it was lovely, that was fine because they paid me a cheque which went into a separate account and I simply paid everybody from that and everything in the garden was lovely. But then of course the old crunch came, you've heard of it have you?

I— I have actually, yeah, there's been a mention

Joanne - Yeah, the odd thing. And that was the first thing to go and we fought like crazy, everybody fought like crazy but you know it was no good. If you've got more than £21,000 savings then you pay for your own care and it is just so narrow minded of them because £21,000 isn't going to last at all at £900 a month if you think. And then you're going to be destitute and then they have to take over the care. What's going to cost more? You see your full time care or, so I mean it's not even looking at people losing their independence so that went. And so that meant that I had to pay, you know, find the £900 a month from my income which of course was dwindling because of this recession (yeah) you got no interest or anything so erm so I mean I did have a difference of opinion shall we say with one of my carers who said well you should just spend all your money and get down to the £21,000 and then they've got to look after you, you see, and I said what do you think they will do? Do you think they will keep this house going? You know, pay for the heating and everything because I would have no income then, well apart from my pension, pensions, erm and she said well that doesn't matter you know they've got to do it and I said yes but they're going

to say right it's cheaper to put you in a home, right you're going in a home you see (yeah) and she said well you might die before then (oh) and I said yeah I might but as the chap who comes round to do all the heavy stuff in the garden said, I started coming round here just before you were 60 and you were saying well I'm not going to live much longer, MS doesn't make old bones because it doesn't, and here you are 70 and you're still saying well it's not worth doing that because I'm not going to last much longer, you know, so... I mean ok I know that I could die tomorrow and I also know that there is a very faint chance that I could go on past the limits of my savings (yeah) and there's no way I am going into a home!"

Joanne's story shows how precarious the situation of a personal budget recipient is; she had previously been in receipt of a substantial allowance to cover her care costs but this had been withdrawn as a result of government changes to funding. She was left to fund her own care and was understandably concerned about how long her savings would last and what would happen to her once she was no longer able to fund her personal carers. Jerry also had concerns over how long he would be able to fund his mother's care home place:

"There's not much money left (laughs) she's going through it at such a rate. Another year and you know we'll be into a new scenario. But yeah just trying to keep on top of it has been a job that's ... taken a lot of my time and effort to do and I'm glad that I can do it. ... but that's a sort of on-going business that I find I'm doing from time to time. And it seems like at the moment she's got another year left of savings and so I'll be talking to the home about what to do, what happens after that. I'll have to make an appointment and go in and do it properly with them but they seem to think, you know, informally when she went in we were talking about what happens if the savings run out and they were saying well, you know, we can sort things out alright and we don't have people moving off to other places because they can't afford to, you know, so whether they just adjust their fees to as much as the council wants to cough up, do it like that, I don't know what actually happens. Whether the council pay the whole amount because it's Chichester and they can, I don't know. I mean I just don't know what, it seems like the council have a figure that they go by for what a nursing home ought to cost and they pay up to that if yours costs more than that then you've got to find yourself somewhere else."

Heather spoke about how her mother's care would be something they arranged together and she was more concerned with dealing with the current crisis than looking to the future:

"Thankfully she's good at working with me, we work together so we can manage things together and I haven't got siblings to fight and argue and what have you. At the end of the day I will do my best for her and it's in my interest not to embezzle or anything else ... my attitude always was spend it on yourself mother and that's still my attitude you know, if you've got the cash there to get two lovely girls looking after you then that's the way the money goes. Yep so there we are for the time being."

Heather's concluding comment about the care being settled "for the time being" links to the calls for choice to be reconceptualised as a dynamic process, for example, as the decisions that have been made will need to be adjusted and reconsidered as Heather's mother's situation changes (Glendinning, 2008:462).

The discussion over the length of time that funds would cover the cost of care was put in terms of what would happen once the funding ran out rather than a question of how much longer the older person would live. There was no talk of death other than discussion of people that had already passed away. Participants that were caring for their older relative at the time of our conversations were concerned foremost with the current care arrangements. There was an understanding that the care choices that were being made were not final and that further adjustments would need to be made as circumstances continue to change.

Discussion

To understand how older people and their families negotiate formal care choices, the narratives presented in this chapter set out the elements that participants described as most meaningful in their experience of arranging formal care. It is here that, in theory, the personalisation agenda would be most visible.

This chapter began by exploring the difficulty in accessing information about formal care services such as the quality of different care homes, but also information about other services which may make life easier for the older person and their carer. In line with Baxter, Glendinning and Clarke's (2008) findings regarding information gathering, there is a difference between crisis situations and those where there is some advance warning of future care requirements. In situations where a care recipient is in hospital recovering from an illness or where informal carers are still able to cope, there is time to collate information and deliberate on the options available.

Yet, while participants had time to look for information, they described experiencing difficulties in their search, such information being hard to find, and social workers providing them with too much information or with information that they didn't feel was relevant to the support they wanted. This is in contrast to the view that information should be in an appropriate format, easy to find and of high quality (Baxter et al. 2008). For example, Andy describes seeking information on services that would support him so that he might care for Maggie rather than services that would provide care for her directly: he was looking for services to support him with household tasks, giving him time to care for his wife, not services that would take over her care. As Mol (2008) argues, care is about people working together towards a result and the important element is time, but the 'logic of choice' leads to the need to delineate the care that is on offer as a package available for the consumer to choose and care becomes a 'product' that changes hands (Mol, 2008:21). For Andy, the 'logic of care'

would provide him with support to allow him extra time to care for his wife rather than a specific product that would take over a care task. The range of experiences that were presented show that the timing of the decision to put formal care arrangements in place varies widely between families and depends on the rate at which the older person's care needs change as well as the type of support that is preferred.

The discourse of personalisation emphasises that the expansion of choice in care services is meant to lead to the empowerment of the individual (Clarke, 2005). The earlier discussion of the sharing of decisions in health care has shown that individual decision making is not always the preferred option and this was paralleled in the narratives where family members chose care homes for their older relatives. The way that Jerry decided on his mother's care and arranged it without her knowledge could be viewed as "making moral judgements about the best thing to do in difficult circumstances" (Barnes 2012:18) rather than an attempt to disempower the older person. It is a continuation of the act of caring, relieving the older person of the burden of having to contemplate a future of increasing dependency. This reflects the finding of Schneider et al. (2006) that older people may prefer others to make decisions relating to their care rather than having to decide themselves, particularly in situations where the decision relates to a serious illness or condition.

Stephen's comments about how his parents found it "very difficult to accept the loss of abilities that they were experiencing and the loss of control over their world" highlight how such difficulties may lead older people to leave it too late to make care decisions. This contributes to the burden of choice regarding formal care being left to those who provide informal care; they make the choice of formal care provider in order to ensure the best care for the care recipient rather than to try and disempower them.

The different family situations were also emphasised in the descriptions of attempts to introduce formal care into the homes of older couples. A couple's experience of care is a shared experience as they both have to accommodate strangers coming into their home and becoming involved in their personal routines. It is in these situations that mechanisms of power can be identified and Foucault's process of 'subjectification' takes place, 'subjectification' being the historically located, disciplinary process that influences the decisions and actions of individuals (McHoul 1993:3). For example, Mrs Cole continued to undertake care tasks despite the presence of formal carers. Hoggett (2001:40) argues that choice is not always the result of reasoned deliberation, most choices are made on impulse in urgent and contingent encounters requiring on-the-spot decisions as our own and others'

needs, expectations, and feelings press in on us. Mrs Cole may have felt dominated by those around her who insisted on the change in arrangements. Her actions appeared to be impulsive rather than planned or contrived as she continued to jeopardise her own health. Sue encountered a similar difficulty when she arranged formal carers to help her father after he had a knee operation and had difficulty moving. The way he sought to ensure that all care tasks were completed by the time the home help carers arrived could be regarded as 'passive resistance', an individual acting in a manner that bypasses direct confrontation, but nevertheless achieves desired outcomes (Lorentzen, 2008:74).

Whilst some participants viewed the introduction of formal care as intrusive and disempowering, others saw it as a necessity that enabled them, or the person they cared for, to remain in their own home. In situations where the formal care supported an informal carer successfully, it was described as being managed in a way that ensured that it supported the informal carer without taking away from the care that was already given. For example, June did not view the need for formal carers as a criticism of her ability to care, but understanding what her husband was comfortable with, she planned the care tasks and distributed them so that her husband was as comfortable as possible. Joanne, who employed her carers directly, was able to select carers to match her personal preferences and appeared to find personalisation helpful in that sense.

The participants described how the management of formal carers required a certain amount of emotional labour on their behalf. The adoption of a dialogical approach to analysis requires a questioning of the narratives to determine who is "holding their own in the story" (Frank 2010:77). Frank (2010:77) asserts that "holding one's own" can include avoiding a threat to the value of the self. This avoidance is evident in June's discussion of her husband's preference for older carers over the younger carers who reminded him of his grandchildren. June said that she didn't want to create bad relationships and so did not criticise the younger carers but instead arranged for the more intimate care tasks to be undertaken by the older carers with whom her husband was more comfortable.

Joanne spoke in more detail about the management of her emotions when dealing with her carers. She contrasted this with a story of another care recipient who displayed what the carers considered to be unfair responses to their care. In Hochschild's (1983:83) terms this is 'inappropriate emotion'. 'Inappropriate emotion' may be seen as a non-payment or mis-payment of what is due, an indication that we are not seeing things in the right light (Hochschild, 1983:83). Whilst Joanne considers her relationship with her carers as a friendship

there is still an element of inequality because Joanne relies on her carers to get her out of bed and washed and so on. It is perhaps because of this inequality that she feels that she should provide more in terms of emotional gestures or emotional gifts, things like smiles, attentive listening and appreciative laughter (Hochschild, 1983:84). Joanne felt that providing a comfortable and happy situation for her carers to work in would ensure that they continue to provide care and this shows how formal care is viewed as more than a task undertaken for monetary reasons.

Recent discussions of the personalisation agenda reflect that choice and control are only meaningful if they go hand in hand with support, both family support and support from professionals (Glasby & Needham, 2014:189). However, when describing interactions with care professionals, the older person in these narratives does not appear to be supported or in control of their care. Participants described times where they wanted to make formal complaints because of problems with the care of their relative but the relatives felt vulnerable and resisted complaining due to concerns over the consequences. The difficulty of challenging poor care was described by participants who were keen to report failures but who were prevented by their own concern, or the concerns of the care recipient, about the consequences of such complaints

A critical aspect of the interaction with care professionals was that the participants described being treated as a specific problem, as a leg or a knee rather than a whole person. The issues resulting from this ranged from the inconvenience of repeating information to different specialists to the more serious one of carers being discharged from hospital without taking into account that they will be returning to take on responsibilities for the physical care of another.

The importance of taking a feminist approach became evident in the stories of women being expected to continue to care for their husbands and daughters expected to care for their parents. In the narrative by Sally regarding the social worker's criticism of Sally's mother's home, it seems that Sally was the object of the assessment rather than her mother. These judgements from the social worker were particularly difficult for Sally because her brother was the main point of contact for her mother whereas Sally had little day to day contact. Sally's comments about her childhood suggested a difficult relationship whilst she was growing up and this was clearly an emotional and upsetting subject for Sally. The assumption that she would, indeed that she should, have been providing support for her mother shows that gender stereotypes persist in care services.

The personalisation agenda aims to move towards a greater emphasis on individual choice and personal responsibility and this is reflected in the funding structure with fewer people being eligible for state support and greater numbers being expected to self-fund their care. This leads to concerns over the way in which future care will be paid for and how care arrangements may have to change to reflect dwindling resources. This was discussed by several participants where current arrangements were satisfactory but there was an awareness of the unpredictability of care needs. Joanne spoke of how her benefits package had changed enormously over recent years and, in common with other participants, her concerns over funding related to would happen once the funding ran out. She also described how the reduction in funding has led to her feeling uncomfortable and uncertain about the future. Heather's concluding comment about the care being settled "for the time being", since the decisions that have been made will need to be adjusted and reconsidered as Heather's mother's situation changes, links to the calls for choice to reconceptualised as a dynamic process (Mol 2008; Glendinning 2008). The concerns over funding contribute to the experience of care in later life as being a time of instability.

This chapter has explored the ways in which the policy emphasis on individual choice impacts upon decisions relating to formal care in later life. The narratives presented here have not described individualised empowerment of the older person nor provided a display of individual choice and control, as framed in the policy agendas. Rather, the narratives show that the introduction of formal care into the home indicates that care relationships are shared, not only by the care giver and care receiver but also those who are part of the care receiver's immediate network. The following chapter explores specific practices of caring and examines how informal and formal care arrangements connect and overlap.

Chapter Six: Practices of Caring: “Drinking tea out of a bone china cup.”

Introduction

This chapter examines the practices of caring. Tronto (1993:104) suggests that we can recognise care when a practice is “aimed at maintaining, continuing or repairing the world” and we can understand the limits of care by noting what is not care: the pursuit of pleasure, creative activity, production or destruction. The use of the word *practice* implies a sense of the everyday both in the sense of life events that are experienced by a significant proportion of any population as well as the everyday in the sense of activities which seem unremarkable (Morgan, 2013:6). As discussed by Winance (2010:11), to care is to tinker, to adapt, adjust, pay attention to details and change them as necessary and to reflect this ongoing process the use of the term ‘caring’ is considered to be a more fluid term than ‘care’. By emphasising ‘doing’, it also focuses attention on the relationships involved in care (Bowlby et al., 2010:40). The purpose of taking this approach here is to explore the narratives about participants’ views on what tasks or acts constitute *care*. The practices of caring that are examined are the way in which informal care continues alongside formal care, the role that managing medications plays in daily life and the importance of food as part of care. The chapter will also explore the notion of the commodification of care as well as the emotional aspects of later life that were an important part of some of the participants’ narratives.

Informal Care Alongside Formal Care

As Wilson (1997:521) points out, although the move to the nursing home might be expected to alleviate some of the pressure on relatives to provide daily care, many people continue to experience time pressures within their daily lives, with the need to visit as well as continue other supportive roles. This aspect of family care was discussed by Jerry, both in terms of the care that he continued to provide to his mother but also in the difficulty that he had in letting go of his care role after his mother was admitted into the nursing home:

“... she’s running out of clothes, she’s sitting there, she’s put on a lot of weight, her clothes don’t fit anymore and we have to do something about getting her new clothes because actually the home isn’t and so
I - That’s quite tricky isn’t it because you can’t really take her shopping
J - You can’t take her shopping no
I - and she can’t try things on
J - No, no. I bought her a nightie a few months back and I [said] ... try it on sometime and see if it’s ok and if it is I can get another one, get some more but if it’s not ok I can take it back and change it and that sort of thing but that’s the last I’ve heard of it, you know, they haven’t come back to me and said “oh it doesn’t fit” and of course because

I was only trying this out her name wasn't on it and so I don't know what's happened to it. It's the sort of little thing that if it was in your own everyday life you'd just sort it out as time goes on, you'd go back to the shop or something if it doesn't fit and that sort of thing but because it's her problem rather than mine in a sense I can't, it's more of a problem for me to go there and try and find somebody that might possibly know about this nightie which could be anybody, I could be all day just trying to sort that out. You know and, you know, I've got my own things to deal with as well and actually then important thing for me when I'm down there is to be sitting there talking to her because that's why I'm there and that's what she wants."

It has been noted that clothing provides an interface between the body and social meanings attached to it: "they are the vestimentary envelope that contains the body and presents it to the world" (Twigg & Majima, 2014:25). Clothes are a way of expressing identity and if Jerry's mother only wore nighties then it was important that they should fit properly. Jerry also linked this issue of identity with his mother's need for companionship. He spoke about her interaction with the staff:

"... I think that is good but the quality of the conversation is important as well and it is a one-way conversation well it is a conversation but it's mostly, well with me just trying to keep something interesting going and I can make a joke about and next time I see her, you know and all that kind of chatty stuff I can, I can relay that to her and it's personal experience and it's just like a bit of a joke for her"

Jerry was seeking to keep a connection between not only himself and his mother but also with his mother and the outside world. It has been found that in the period around the move into the nursing home can be particularly traumatic for many relatives, involving a process of sudden adjustment to being without the older person on a day-to-day basis, as well as the need to undertake many practical tasks (Wilson, 1997:524). Relatives may seek reassurance by checking if the older person has been involved in any activities, asking about their dietary intake and appetite, and observing how care staff spoke to their relative (Wilson, 1997:522). Wilson (1997:524) found that once a placement had been agreed as permanent and the initial adjustment had occurred, part of the on-going process for relatives was to create and maintain a role within the home.

Jerry spoke of an issue with the television that showing his difficulty with letting go of the caring role that had been such a huge part of his life before his mother moved to the nursing home:

"Oh and the other sort of thing that I found that was not so important she never got the hang of using the remote control on the television so I was planning what she needed to watch and popping in every half hour to change channels for her because she couldn't do it herself because she didn't, you know, couldn't work out how to do it. So letting that go has been a bit difficult for me I think because I don't know what

kind of help in that way there is down at the nursing home because a well they just sit in and chat with her, not very much I don't think so she sits in her chair looking at the birds all the time and she's got the television on but she can't actually watch something she wants to watch. Whenever I go in to see her it's on and she'll say oh turn that off I'm not watching it. What a shame that it's not something, before I leave I'll scan through and find something where there are programmes on where she will be interested in until it's bedtime, that sort of thing so that she can watch without having to change channels. But I suppose that's relatively minor but I just think there's so much, knowing what she likes and what she doesn't and there's 90% of what's on she doesn't watch so 90% of the time she's going to be watching something she doesn't really want to watch and that's a bit sad, you know but where do we go from there... I gave them, I laminated an A4 page with all the tv channels that she likes and doesn't like and the sorts of programmes she likes and doesn't like and it's still there somewhere but it's never out so whether anybody makes any use of it."

As Jerry found it difficult to let go of his care role with regard to his mother, he found other ways to continue that role, by laminating a list of his mother's TV preferences. He mentioned that he wasn't sure that anybody referred to the list but it seemed to be reassuring to him that he had made it available. Despite his difficulty in letting go of the full time care role Jerry did still feel that he was still an important part of his mother's care:

"So I feel quite lucky in a way even if it is still, we feel a bit, still feel a bit restricted in what we do. We're planning a long holiday in the summer, we went away for quite a long time last summer and my brother was obviously, you know, going to see her more often. I don't know how much more often but, you know, he felt in the frontline then. If we do go away for a little while we tell the home and they can ring him instead of ringing here if there is anything but we still feel a bit restricted that while she's there that we still need to be here and be in touch and we can't. I mean if she wasn't there I quite likely we would like to shut up the house and just go off for some months. Go travelling wherever and just enjoy not being here and just have a lot of fun for a long trip."

In addition to being available for companionship and emotional support for relatives in the care home, Penny described how she was continuing to do her grandparent's washing. She spoke about it in the context of the 'Take a Break' scheme where Penny was receiving a small amount of money to do care tasks for her grandparents but she was not sure whether she was still entitled to that now that her grandparents were in the care home:

"I had to say to the social worker yesterday, you do realise that money's still going in there? It's still going in there and she said oh thank you for telling me, you know, obviously we are not going to be using that now blah blah blah because I'm not needed but that money was still going into that pot when it could have been going somewhere else, you know, it's just dead money to be honest I have costs now I do all their washing for them. The home won't do their washing so I'm going up and I am doing it but apparently I'm not allowed to be claiming it. I have taken money out for petrol here and again which I'm going to get told off for because timesheets and stuff have to be filled in and, you know, but it's expensive, petrol up there all the time,

washing powder all that kind of stuff and you know, you have to kind of really wash it because obviously. Which I have no problem in doing, believe me, whatsoever it's not a problem but it's just a strain on lots of things but, there you go, that's just life isn't it? That's life".

Penny was continuing in her role as carer for her grandparents by continuing to do their laundry whilst they were at the nursing home. She remarks that she is incurring costs which she cannot claim back through the 'Take a Break' scheme but despite that she does not have a problem in continuing to do the laundry although it is a strain when she has work and children to contend with at the same time.

The above section has shown that the move from informal care to formal care does not lead to an immediate cessation of informal care. Not only do the older people who have moved into formal care need the continuing support of their relatives but those who have been informal carers need to come to terms with the changing relationship. This overlap of care can be seen as sitting midway along the continuum of care proposed by Milligan (2003). It shows the boundaries between informal care and formal care become blurred and the role of informal carers continues to be important to the well-being of both the care recipient and the informal carer.

Commodification of Care

It has been argued that the marketisation of care turns care into a market product whereas the commodification of care denotes a more pervasive material change (Hoppania & Vaittinen, 2014). Care is simplified, subdivided and rationalised to the extent that it is turned into a commodity, it is described as a transaction rather than as social relations (Green & Lawson, 2015:41). This commodification of care together with the divisions between health and social care systems can lead to difficulties for those with 'intermediate' needs when the care they require may be considered by each system to be the remit of the other (Lewis, 2001:345). Penny described such a situation when her grandfather had a wound or a growth on his head and no care was provided:

"During this time he also had a lump on his head which has continued and his head was kind of, was horrible, but it was kind of going green and scabby and horrible and there was no daily care for the head. No daily care for the head, nobody was really interested. It was always everyone else's responsibility and then ultimately the responsibility was left to my Nan to deal with that. Which was all, I personally think, contributed to what has now happened to my Nan ... But you see the whole thing between times when Nan was having the heart attacks, you know, nobody did anything about his head. You know, his head was green and weeping and itchy and disgusting and he had a great big lump coming out of it. He's just had it removed, it

was a tumour it was a malignant tumour but nobody, I was saying to this other social worker, well what are you doing? You need to get somebody to come out every day, district nurse, whoever, and dress that head cos when they were in Heathfield the first time the nurses worked on it every day, gross but they sort of scraped it, got it back to normal and he came out and he had a shiny lovely bald head. Soon as he got home it started to go green again. This is no reflection on my Nan because my Nan isn't trained in doing stuff like that. She was just washing it, maybe not particularly sterilely everyday but she was doing what she thought was best. He had sort of sporadic appointments with the dermatologist but no one was interested in the daily care of his head. I was banging on doors, saying to this other social worker, well can you not get somebody to come in, you need to kick some arse here and he was saying well it's much better coming from the family ... I'd ring the GP and they'd say sorry it's not in our remit we don't help people to do that every day. Well by the by my Granddad's head is rotting and actually it was cancer on his head and nobody really did anything about that and the nurse's attitude to me was well you need to get the carers to do, well the carers aren't going to go near that and should they be? It's a nursing thing, and again now, I know he's just had the lump off and he's had stitches and stuff and you know it's beautiful again because he's had daily nursing and that's the point."

Penny's description shows that while her Grandfather's head wound was regarded by health care professionals as a minor problem that could be dealt with by simply washing, they did not take into account the fact that his wife was already struggling to cope with the existing care tasks. This problem was eventually dealt with and care was provided by nursing staff but it is a concern how many other older people face these problems without a family member to chase the appropriate care.

Meetings with health care professionals were described by Andy as being impersonal and uncaring, which is very different to the relationship with doctors that he remembers from his youth:

"I grew up in an age in Scotland when the family doctor was almost one of the family, you knew him, he knew you, he'd known me since I was born practically and when they were on their rounds, occasionally they'd drop in just drop and say "how are you?" A caring relationship, nowadays I think that's gone because the practice teams of doctors seem to be getting bigger and bigger ... So we saw a doctor for Maggie's arthritis a couple of weeks ago. We hadn't seen him before, he hadn't seen us, a very pleasant young man but you were talking to him and to the computer screen because you're just an item of information and I think a lot of the sense of humanity, or togetherness has gone from the NHS and to an extent from social services because they don't seem to follow up. When they think you're a wee bit better they go I'll take you off the list now."

Andy described his childhood relationship with his doctor as a 'caring relationship' but now when visiting his local general practice he often saw a doctor he had not seen before and felt that there was a lack of interest from the doctor and that Andy was regarded as a set of

symptoms, 'an item of information'. Andy also described the problems in sourcing practical help from different departments:

"...Because of my stomach operation I've got to wear a big sort of binder, surgical belt and all sorts of bells and bits of Velcro on it and when they gave it to me they said see how it goes and if it's alright let us know and we'll provide another. And it was fine so I went back to the practice a little while ago and said I'd like another. Oh who provided it so I said well the disability service in Eastfield. Oh well was it from us or from the hospital ... I said I don't know. So in the end I said don't bother and I went back myself to St Stephen's to the disability centre they were a bit vague but I gave them the name of the supplier on the label and the patent design order number and they said that's alright we can arrange that now."

Andy had to negotiate with several departments in order to obtain a piece of medical equipment that was important to his recovery from a major operation. Andy found dealing with the different departments required a great deal of effort and described a department, the disability centre, as being a bit vague until he was able to provide them with detailed information about the manufacturer and supplier. This again links to Peel and Hardings's (2013) study where participants recounted dealing with different departments as negotiating a 'maze'.

The participants expressed concerns that care professionals do not consider the situation of the care recipient, the context in which their care would be taking place and their previous life experience. As Stange (2009) points out, the advances in medicine derive from a focus on a particular problem and this leads to a fragmentation as health professionals focus on their speciality without appreciating its relation to the whole person. He suggests that this fragmentation leads to inefficiency, ineffectiveness, depersonalisation and discord (Stange, 2009:102). Sue spoke about how she felt that she had to chase things up and "make a stink" in order to get her father's care needs addressed:

"He wasn't automatically referred to occupational therapy because it was only a knee not a hip so I had to ... get something from the doctor I think it was saying that Dad was Mum's carer, I had to get something or other before they would agree to talk to him but once he was kind of on their list as soon as he was home a lovely occupational therapist came round with a van full of stuff so they had the raised loo seats, one of which he's still got, the perching stool, the zimmer frame, they arranged for somebody to come and put the grab rail above the bath and the bench across the bath so that he could get in and out across that and she was brilliant but if I hadn't made a stink and lots of noise they wouldn't have done it because it was a knee not a hip and you're not entitled if you have a knee so again that's kind of treating the person as their ailment rather than as a person".

Sue also spoke about how she felt that all of her father's illnesses were not being considered together:

“They weren’t looking at him at a whole person, it was a knee and I think that’s what’s so wrong and that was the problem with the care home as well they were treating him as a knee or a bowel not a whole person”

Penny described the decision to discharge her grandmother from hospital after a heart attack even though she was the main carer for her husband:

“So that was that decision that day with the social worker but then that guy just went in there and said to her well you look alright without, and my Mum phoned him up afterwards and said what are you doing? Presumably you’ve read the case notes? No I haven’t the case notes I’ve just read the medical notes and she’s just had a heart attack she’s had a stent put in so there’s no problem is there? He’d read none of the social notes, none of the background, none of the case, anything. He didn’t have a clue that my Nan was main carer for my Granddad, that my Granddad had Parkinson’s and all this, he just went in, arrogant as hell and said, then he was rude to everybody that phoned and so we complained about him as well. Should that really have to happen? Why are these people in that job?”

Heather also described a need to have her mother’s case reviewed to take into account all her illnesses:

“... I had to request that the GP come in and take an overall picture of her because I’d had different doctors prescribing different things for different things and I didn’t feel that there was one person taking an overall vision of her.”

These narratives show how the commodification of care leads to a focus on a particular problem, symptom or illness. The context in which care recipients exist is often not considered, whereas for the individual their situation in life, their social supports as well as their responsibilities are an important part of their identity. By reducing them to a single illness or care task leads to a dehumanisation of the individual and a feeling that they are not being ‘cared for’.

Managing Medications

Medications are an important aspect of daily life for older people as medical problems can increase with age and a variety of medication may need to be administered (Duerden & Payne, 2013). Taking medication can be seen as the practice of self-care, in this sense ‘practice’ can be taken to mean something that is undertaken frequently (Morgan, 2013:6).

Ken and Martha live in a self-contained flat in a retirement village. The institution provides carers for Martha who has dementia. While her husband Ken continues to care for her, he has his own health problems to contend with. At the beginning of our interview we discussed their care needs and they began by showing me the pill package that is used to separate Ken’s medication into separate dosages. This act of displaying the pill package set a precedent as

they later brought out more artefacts for me to look at, photographs of their family, a CD of their favourite music. These artefacts were important biographical details for the couple and were used to express agency in terms of who they were as a couple, what they have done and experienced in life and as a way of giving meaning to the past (Gubrium & Holstein, 1995:562).

This narrative is presented in a slightly different format to the other narratives as the discussion was a three way conversation. Ken and Martha often spoke over each other or finished each other's sentences:

K – We get all our tablets delivered here and then the girls come in and see to her because I'm an individual (laughs) I'm separate.
M – He's had a heart attack
K – I've had a couple of heart attacks
M – So he mustn't do too much for me, you know what I mean
I – Right
M - So they come, he does though believe you me. What goes on behind closed doors
K – I've had prostate and all that but it don't worry me
M – The tablets are delivered in this little box look. I'm getting up, I'm up, I've got to move some of the time Ken, that's his only trouble is,
I – he cares too much
M – He mothers me, though he should be me Dad, he mothers me. This is how the tablets come, this is his tablets.
K – The other way, turn it up,
I – Oh wow, this is brilliant
M – This is a new one this is, this is the first time they've come like that. They used to be all clear
K – they colour them
M – They colour them, well it's good 'cause it's different days because when they're all the same colour, you know, different people have got different problems.
K – Hers is the same thing but smaller but the women, the carers come and give her hers
I – oh ok
K – they give her them
M – It's fascinating isn't it?
K – marvellous
M – what's it called? Ozy box I think it's called but it's the first week they've come with colours. Very pretty isn't it?
I - Yes (laughs)
M – (Laughs) might make people look at them, they'll pick it up, ooh I've got to take this tablet.
K – I think I take more tablets than what she does (laughs)
I – (laughs) You've got a lot to take first thing in the morning haven't you?
K – Yeah I take, eight I think
M- Eight in all
K – and then those at dinner time and that's me lot
I – But it makes it so much easier like that doesn't it?
M – Oh yes
K – Oh it's marvellous

I – You haven't got to think about it

M – No, no, no, the only trouble is. Each of those little compartments has got a lid on it and that's the trouble (laughs) getting it off, cause it's only a bit of plastic. Once you get the corner, you're alright, you know. Nothing's straightforward is it?

Whilst Ken is able to manage his own medication with the help of the box, Martha's medication is managed by the carers. The importance of showing that Ken has his medication organized and is managing his dosage correctly could be seen as an acceptance of the medical 'gaze'. The 'gaze' is not only about medicalising ageing, it also highlights the way people are encouraged to 'work on themselves' as active subjects taking personal responsibility for their health (Biggs & Powell, 2001:4).

The adherence to a medication routine links to what Foucault (1988) called 'technologies of the self', the practices that individuals undertake themselves, not because they are subject to an external force but because they believe it is in their best interests, having internalised the norms that have been established (Howson, 2013:158). By taking medication the participants are continuing to respond to the public health discourse that encourages individuals to observe and monitor their own health (Howson, 2013:158).

The management of medication was also mentioned by Andy who wanted to show me his system for managing Maggie's medication. He explained that it was very complicated and that Sue had devised the system that involved a notebook and the tablets:

"Maggie's drug regime is quite complicated and we've had it changed a bit just recently we had dihydrochloride substituted for tramadol but that's the sort of way we organise it. Sue drew up the chart for us (Notebook with tablets in a folder and daily schedule to tick of two hourly dosages when delivered) In addition to that, that's every day, in addition to that there's one memory pill every morning and then on a Tuesday her eight mesatextrate of a morning and on a Friday there's one folic acid because the mesatextrate and folic acid go together so that's the way it goes.

I - Quite complicated, and a constant interruption to your day if it's every two hours you have to really not go out for very long or take the medication with you

A – We take the book with us and the pills and just ask someone for a glass of water as we did this morning down in the Driftwood Café, we went in there and they're sort of used to it in a way I think. It works out quite well".

By explaining the complicated instructions that went with the variety of medications, Andy was situating himself as a competent carer. In Foucault's terms this activity of managing medication would be termed an 'ascetic practice': an art or technique learned by practice (Heyes, 2006:139). Such repeated practices are considered a "necessary condition of effective citizenship and relationships. We owe it to ourselves and to others to constitute ourselves as

ethical agents through ascetic practices” (Heyes, 2006:139) . Andy takes the management of the medications very seriously and ensures that Maggie has the correct medicines even if they are taken out for the day by Sue. Although I was not seeking to judge the care that Andy was providing, I wonder if he saw me as an expert on care and that I would perhaps be monitoring the quality of the care that he was providing.

Mr and Mrs Cole also had a variety of medications that needed to be taken at regular intervals to manage Mr Cole’s Parkinson’s and Mrs Cole’s heart problems. Penny would help Mrs Cole manage Mr Cole’s medication but also monitor that Mrs Cole was taking the correct medication.

“Generally he’ll be unresponsive for a couple of minutes and he’s had a TIA cos it’s just the way Parkinson’s is. Not only this, my Nan then had to cope with medication as well so both on a huge amount of medication. I was doing all of her meds at the time ... she was on meds, she had a stroke as well ... actually it was during that time she had a stroke so last year she had a stroke and I went and stayed in the hospital with her for two days... Then, of course, a couple of days later she had to come back in and start dealing with all this again.”

The increasing amount of medication was also an indication of Mr and Mrs Cole’s deteriorating health. Each time that Mrs Cole had a stroke, Penny had to organise temporary care for Mr Cole as well as support Mrs Cole by visiting and even staying with her in hospital. By the time Penny’s grandparents had moved into the nursing home Penny had become an ‘expert’ in their medications:

“I mean it has slightly kind of relaxed now because obviously they’re where they are and they’re safe and they’re well and all that kind of stuff, reasonably well, but they’re safe and they’re warm and they’ve got nursing care and somebody there if necessary which is brilliant because tablets are timed, they’re brought up the tablets in little pots, because we noticed when my nan went home that she had missed out a few of her daily doses, that she wasn’t able to do that at that point. Whether or not that contributed to the second heart attack or what I don’t know because I don’t know the drugs anymore, I used to know all of their drugs, I used to go up there every week and put her drugs in pots for her, I used to know all of them, I was like a drug czar, I knew what I was doing, I didn’t know how to pronounce them but I knew what I was doing with it.”

Penny’s repetition of “they’re safe” serves to justify her statement that she can now relax, she has not abandoned or given up on her grandparents. However, her role as manager of their medications was not over and she spoke of the difficulties of ensuring that her grandparents had all of their various medications when they were in short term care in the nursing home:

“Another hassle is, obviously their doctor is in Tyfield because that is the nearest to Eastby which is a pain in the arse. They were getting all their drugs delivered from there. To do the whole, where they’re at a nursing home the doctors will only supply

their drugs if they're not in the area for about a week. And the home can't register them with their doctor because they are only a temporary resident. So, they're both on a million drugs in little dosing boxes per week so it was a situation of again the family had to go in between the two and go right so what are you going to do and they would say right well maybe we'll do the drugs for another week but you're going to have to collect them and take them up there. So I was running around between surgeries between work and everything else to that surgery to take the drugs up to the home and the home would ring me and say, on a Saturday, and say we've got no Madopar left. Well what do you expect me to do on a Saturday afternoon? This is a drug for my Granddad what am I going to do? It was just all mental so we made them, we registered them with this doctor near to the nursing home so they are temporarily registered with him which is brilliant because then they can just get the drugs and they're sorted. I don't know why they didn't do that in the first place."

Penny's narrative describes the difficulty of continuity of medication when people are placed in nursing homes for respite care. The responsibility of medication appears to be a grey area between informal and formal care. These difficulties in arranging the medication for family members who are in care homes for respite or short term care appear to be unexpected. It would be reasonable to assume that the care homes would have systems in place to ensure that prescriptions can be filled and that medication is given continuously and so avoid the risks that any break or lack of medication may entail. In fact, the difficulty in the delivery of medication was mentioned by another participant. In that care, there was an additional difficulty in that the care recipient did not have a close family member to keep track of their medication or to ensure that they are receiving the drugs that are prescribed to them in the care home. Barbara spoke of her experience with her friend Stewart that she had supported whilst he was living at home but when his needs increased his family took over and arranged for him to go into a care home:

"In the end he couldn't go to the hospice, they didn't have room for him and his cousins decided that he should go into a care home near them ...because he was ninety one, a lot of his friends couldn't drive it was a long way for them to go and the care there was appalling, it was awful, a lot of the staff couldn't speak English and he had a hearing aid so of course found it harder, and they, at the end he needed ...oh what's the thing you have when it's awful pain? (I – Morphine?) Yes he was very bad one day and they called the doctor in the evening and it wasn't their normal doctor, apparently he wrote out the wrong prescription. They didn't phone his relatives to say can you go and get this medicine, waited till they came in which was later in the day, this was on the Saturday, they then took the prescription to the chemist and he said I am very sorry I can't give you this, prescription's not right ... He'd been left in pain from the Friday evening and I rang ... and I said well what was it he wanted and he said, um oh um, morphine, well we'd been given some morphine for Stewart to keep in his flat in case he needed it. So I rang up the home and said I've got some, I went up with it and they said that's not what we want we've got that, it was to be injected. The following day I said I must go up, I went up there I said 'have you got the prescription now?' because they said they would get a new prescription and they looked at me and

said ‘yes’ but we can’t get it. They had nobody to go and collect medicines at the weekends and it was a very expensive place, no one to do that, they hadn’t let the relatives know!”

Barbara spoke of the care at the home as being awful and goes on to describe the care home’s failure to fill a prescription for morphine that had, firstly been incorrectly written by the doctor, and secondly the care home had no staff to go and fill the prescription. The earlier comment that ‘they’re safe’ seems questionable when there is no assurance that care home residents are receiving the appropriate medication to manage either long-term conditions or severe pain.

These narratives of medication were important to the participants possibly because they formed such a large part of daily life. Andy was responsible for monitoring Maggie’s medication which had to be administered every two hours, Mrs Cole was responsible for administering her husband’s medication which had to be given every four hours. Their granddaughter Penny described how she was aware that there would be problems if the medication was not given on time but was not clear about what those problems would be. This emphasis on the timing of medications places a high level of responsibility on the informal care which together with the very intrusive nature of two or four hourly dosage made the medication a prominent feature of daily life.

Food and Care

Food is closely connected with issues of care, caring for someone is demonstrated in the way food is prepared with implicit reference to the health and well-being of the care recipient (Morgan, 2013:101). In considering food and its connection to care, the nutritional value is not the only aspect to ‘nourishing care’ (Mol, 2010:217). Mol (2010) explores how it is not only the substance of food that deserves attention but that the practice of eating is at least as important and, in that context, ‘cosiness’ or comfortable surroundings play an important role. Jerry spoke about the disappointment in the food arrangements at the care home where his mother was living. Jerry made a point about the food and crockery – aspects that could be personalised to suit individuals but instead appear to be operated on a minimal cost basis:

“I think paying that sort of money I expected a bit better in terms of the food and the crockery and things like that it’s all kind of chunky, dishwasher proof stuff that you know, that like in a café or somewhere where you just. I mean, I don’t mean a, I just thought that a place like that everything is very nicely done and it would’ve been nicer to have nice china to drink out of and, but they do bring round, you know, would you like a sherry before lunch and that sort of thing but she doesn’t drink very much so (laughs) if she has a glass of wine she probably only drinks the first two sips of it and

that's it but she does like drinking out of bone china and why not, it means you can't put it in a dishwasher, you've only got 30 rooms it's not a huge washing up job to do."

In Mol's (2010:217) discussion of cosiness she refers to the importance of the table setting although not directly to the quality of the crockery that is available. Jerry's comments echo the findings of Mol (2010:220) who suggested that choice is an important part of 'nourishing care' but in her study the choices available to nursing home residents were restricted to selection from a menu and that selection had to be made weeks in advance. Jerry described the limitations to the choices that were offered to his mother:

"Oh and the timing as well, the food, I mean she likes, in the, for her supper, the last thing she has before she goes to bed it comes about before 5 o'clock and it's a few sandwiches or something or it's a bowl of soup. Well, what she'd like is something a bit more, you know, a bit hot, a bit more substantial and a bit later like 6 o'clock or 7 o'clock and of course the staff aren't there then so that's one of those things you're not going to negotiate. So, I mean 5 o'clock to her is teatime not supper time (laughs) she might have a cup of tea and a slice, a scone with a bit of jam or something but she wants something more substantial later. That's what she's always been used to."

Diet and the discipline of eating well are also associated with technologies of the self (Foucault 1988). Rose (1996:129) identified three ways of relating to the self: epistemologically (knowing yourself), despotically (mastering yourself) and attentively (caring for yourself) each of which is a different kind of technology of the self. By denying Jerry's mother the agency to determine when and what she eats, it could be argued that she is denied the power to care for herself and to master herself.

For June, preparing food that her husband enjoyed was not only a part of care it was also an act that was strongly linked to emotion because it was a fundamental part of the way that she cared for her husband. She spoke about her problems with the hospital food as an example of a time that she cried. This was the only time she spoke of being upset in this way:

"I didn't obey the rules in hospital (laughs) I did my own thing. I must tell you, this was one, well I actually I cried, I think I was a bit down but I had one staff nurse was very nice and she said your husband's not eating at all. Well he wasn't a fussy eater but he wasn't very well and I used to give him nice bits all done nicely. They gave him about six times too much (yeah) there was, actually there was not much wrong with the food. I am being honest because I tasted the soup, the soup tasted quite nice but it was always luke warm. Would you like to drink luke warm soup? (no) No, no. The same with the dinners, it was, they should give you child portions when you're ill (yes) and there was this huge plateful and he had a look at it and he just didn't fancy it so anyway the staff nurse said, I've got an idea, she said, why don't you bring him in a little bit of what he likes and microwave it here. I said, can I do that? She said, yes. I said, brilliant. So I took him in, you know, a nice bit of salmon with just a bit of

cauliflower and one new potato on a plate. I did that, you know, different things for four nights with the staff nurse. He ate it all and then the fifth night I went in, it was a different staff nurse. She shouted at me, she says, "you can't do that here. This is against the rules, take it away. I'm not having it here". Absolutely awful, actually I went and cried because I wasn't strong enough at that time to stand (yeah) I said, look I've had permission to do this before and she said well I'll look into that then. And that is, you have a lot of cross (yeah) and then the other thing was, he never liked hot drinks, not coffee or tea, so but he used to have cup-a-soup at night so I said to one of the nurses, I said could I have access to a kettle, so I took him, yes she said no problem, so I took in a mug and the packet and a few nights I gave him the cup-a-soup which he enjoyed and of course one night I had somebody else – you can't use the kettle you might burn yourself. You see I don't do political correctness (laughs)"

Food can also be seen as a way of 'doing family' (Finch, 2007). Rachel cared for her partner Stefan as a couple who 'lived apart together'. She told stories of food as a way of demonstrating that she was caring for Stefan and that she knew him better than anyone because they were 'family'. The discussion of food highlighted the conflict between Rachel and Stefan's children. Rachel took the topic of food as an opportunity to display her knowledge of Stefan's needs:

"... and I said have you done your menu and his son was there and he said yes he's having curry. I said "He's having what!?" He says he's having.. I says "No he can't he can't have curry, I says he's just had a major operation and all, you know, done and he goes in the bowel" he says it's something light and I says "that's not light" (I No) and I was furious and of course the next day I went the curtains were drawn around his bed and one of the chaps said "he's alright, it's alright, he's on the toilet he's been like that for hours". Of course I blew my top cos I'm sorry I know too many medical people and I'm not in awe of them some people are, I'm not! I had a fantastic doctor and, you know, he was nothing like that at all you know, he was lovely, anyway this nurse looked "he'll be out in a while" and of course then when, he looked ghastly, oh he looked awful and there was something wrong his kidneys were giving out, which I wasn't surprised actually and erm I did really get stuck in and I says "Don't any of you" and they fetched this one doctor in and I says "Don't any of you ever look at what these people order on the menu?" I says "his son should have had more sense" I says "but he's a vegetarian so what do you expect" laughs (laughs) Some of my children are vegetarian I mean they eat damn good food and I love it myself although I'm a meat eater. Anyway he said, he said "what he's had a big operation" I said "yes he's had a big operation but you let him have curry" and this doctor looked, I knew he was a consultant, not a doctor he was a consultant and I says "is that the right sort of food for somebody for someone who's had this sort of operation?"

Rachel also spoke about her experience of caring for her husband who had died many years ago. She said that when caring and supporting Stefan she was more confident in standing up to doctors if she saw something that she felt was not right or should be questioned. She was no longer intimidated by the power of the medical professionals. This was demonstrated in a further example where Rachel was concerned about Stefan's appetite:

“Cause we had one doctor come and I said he’s not eating. He said and she says, aren’t you eating? He says well, yes. I says No Stefan you don’t eat, you only eat when I cook for you, you don’t eat otherwise. He says I do I make myself a sandwich and the doctor said there’s nothing wrong with a sandwich. I said ask him what he has on his sandwich. Now I was feeding him salmon, trout, chicken, all the best meats, you know, different ways, whatever, and he said I have lettuce. I said and you have two leaves of lettuce between your bread and butter and nothing else. He says well and I looked at this doctor and I says see what I mean. (mmm) And she never said a word. There were times when I just felt I was banging my head up against a brick wall.”

This concern over food demonstrates Rachel’s perception of good care as care that ensures that Stefan is well nourished. These stories of food practices indicate that those that are providing informal care view the provision of good food as being a fundamental part of their role. Food is an important part of care and it appears important to carers that they not only show that they are ‘doing’ care through the provision of healthy and nutritious food but also that the people that they care about are getting pleasure and satisfaction from what they eat. Daily life practices such as eating, rather than just being more or less pleasant on their own terms, are essential for physical well-being as “eating bodies and the practices of eating make each other be” (Mol, 2010:218). Good food and ‘nourishing care’ can lead to pleasurable experiences in daily life. The ways in which pleasure, sadness and other emotions are experienced in later life are explored in the following section.

Emotions in Later Life

Throughout the interviews the narratives provided by participants were impacted by emotional responses and recounting of some painful and some pleasurable memories. As indicated above, practices of care can elicit particular emotive responses (crying or frustration, for example), as can caring relationships. Arguably, “[e]motions are experienced as fluid processes rather than a static collection of compartmentalized roles” (Hepworth, 1997:174) and as such it is difficult to see how any particular emotion can be assigned as being specific to ageing. Hepworth (1997:175) asks, “in what ways is anger expressed at the age of 70 any different from anger at 20?” The narratives presented here do not suggest that emotions in later life are different to those in earlier stages of life, but they do set out situations in which emotions come to the fore. Brendan confirms that he does not feel differently at the age of 74:

“It’s a bit like age, my father said it to me and I now understand it a bit more, when he was in his 70s I went for a drink with him and he said you know I feel just as innocent and naïve now as I did when I was 15. And I have to say, even today, I feel very much the same way, one may have developed many life skills along the way but I’m always the guy in the office who didn’t know that somebody was pregnant and didn’t know

that somebody was having an affair with somebody else and always asked the innocent, dangerous question. Maybe I don't have the perception for such goings on."

Whilst this story may relate more to Brendan's confidence in social interactions, emotions can be seen as shaped by contact with others (Ahmed, 2014:10). Brendan's view that his competence at social interactions have not changed since he was 15 suggests that the nature of his emotional responses to social situations feel similar to emotions earlier in life. Brendan mentioned his emotions at several points in our conversation, both in terms of his ill-health and in terms of his attitude to ageing. He explicitly said "I think it's important that you realise and perhaps know my feelings, my levels of frustration". Later in our conversation he described how his declining health and advancing age has made him more emotional:

"I can proudly say I'm coming 74 I worked until I was 70 I've never had more than one day out of work in my entire life, I've never ever claimed any benefits and now here I am, this statement says, here I am looking towards a pleasant retirement after a longer than normal working life with an unknown future because of exposure to asbestos which was not my fault ... Erm yeah it, it has made me more emotional. I've always been relatively hard-nosed. One of my, the first job I had to do when I moved to the Thames Valley was make 57 redundant (laughs) that concentrated the mind. I'm more, I read a lot, I will read, my tastes are very eclectic but I'll read a romance and get a lump in my throat where I never ever did. I don't know whether that's about maturity or whether it is brought on by what one has suffered or experienced oneself. Although it's not necessarily relevant now I remember when I was first diagnosed with diabetes, doctor just said, well you've got diabetes, get on with it and I remember going and sitting in the car in the car park outside the doctors and bursting into tears."

Brendan tells a story that reflects his view on the medical approach to depression:

"I find it frustrating that, now that I am in the situation that I am in, I find it frustrating that the main problem, my perception, is psychologically relevant as much as physical and there appears not to be a solution readily available. I've been, nurses have said do you feel depressed? And I said well what do you think? Yes I do. Right we'll prescribe you some anti-depressants and I, that's just treating the symptom isn't it? (laughs) (yeah) Yeah, from an engineering background you don't treat the noise that the engine's making by giving free ear defenders, you get amongst it and change the bearings and get some replacement oil in there (laughs) (I laughs)"

Despite the nurse's lack of surprise at Brendan's depression after his diagnosis of diabetes and other problems, depression is not something that is an inevitable aspect of growing older. Indeed, studies into well-being across all age groups suggests that levels of contentment form a U-shape over the life cycle with life satisfaction levels lowest around the mid-forties and rising in later life (Blanchflower & Oswald, 2008:1746).

In contrast to the depression described by Brendan, Ken and Martha seek to describe to me how happy they are in the retirement village where they are living. I had a brief discussion

with their daughter as I was leaving their flat and she told me that they had struggled to cope before moving to the village. She suggested that neither of her parents seemed to be fully aware of the impact of her mother's dementia and she said that they spoke about "Mum's dimension." The move to the retirement village had been arranged after Ken had a heart attack and could no longer manage to care for Martha alone. Ken and Martha spoke about how happy they are together although within the conversation there was a hint that Martha's condition could lead to her losing her temper:

K – "We never argue, never row (M no) I always said when we got married I'd never row because I've seen so much of that with me Mum and Dad and aunts and uncles and all that business. I said when you row you say things you regret afterwards. You don't think, you lose your temper and you say things and you say, years ago she'd want to have a go at me and I'd just sit there and I'd look at her and I'd just laugh, start laughing. She starts and then at the finish she's laughing cos she sees how silly she is.

M – Yeah I'm the one with the temper. I'm a bit awkward aren't I? I get snappy

K – NO

M – Yes I am, I'm

K – You're making it up (laughing)

M – (laughs) He's so even tempered, bless him but I'm the one that gets a bit shirty at times.

K – Well it's the tablets you're taking innit

M – Well you can blame it on that if you like, I'll let you blame it on that (laughs) but in actual fact it's me darling. You've got the wrong opinion of it.

K – You never used to be like it.

M – Oh well, old age." (laughs)

Ken seems to cope with Martha's temper by attributing it to her medication rather than to her disease. They both sought to let me know how happy they were together. Martha was very appreciative of the care that Ken took to make little things special:

M- "I don't know what I'd be like without him. I mean he's my, I don't know, my everything, aren't you? That song is true.

K – We like our little cuddles. We, sometimes when I do dinner I say let's have a special dinner, we might have duck and pancakes. So I put the two tables there, and I've got, of course, I ain't got a table cloth for them so I put a pillow case on them. And those candles up there because we're not allowed to have candles in here

M – those white ones, they're electric, they're run by battery

K – I turn the lights out and put the candles on."

They also spoke about how Ken used to run a bath for Martha and put candles round the bath, they spoke of how their relationship was no longer sexual since Ken had problems with his prostate:

K – "We've got single beds because, ooh she's a fidget (laughter)

M – I admit it, I admit it darling.
 K – the reason why we’ve got single beds, we’ve got her against the wall and we’ve got a thing on the side of the bed, well they supplied it to us,
 M – Because I fell out of bed
 K – yes so she don’t fall out of bed because she fell out of bed twice here.
 M – That’s me darling, you know what I’m like
 I – But that was after you moved here rather than at home. So you think it was different then?
 M – We had single beds
 K – Oh yes we had single beds at home, we started off in a double bed but once I had the prostrate and that, that finished it.
 M – Yeah love life went out the door
 K – Well that sort of thing did, I mean I had to have ice lollies, I used to eat the ice lollies, keep the sticks to put it in splints (laughs)
 M – there are you (laughs) (I – laughs) He can go on like that all day he can. We’re always having a laugh aren’t we.”

It appears that Ken and Martha work hard at re-framing their relationship as their needs change. Higgs and Gilleard (2015:102) suggest that couples growing older together share settled and stable moral identities which may be challenged by different experiences of health and illness, here by Martha’s dementia and Ken’s heart problems. Higgs and Gilleard (2015:102) describe how these different experiences lead to the re-positioning and re-framing of their shared ties and how this re-ordering may take place without any break in mutual feeling for and with each other. Indeed, Higgs and Gilleard (2015:102) could be describing Ken and Martha’s ‘constancy of affection’ as the couple reminisce and speak of times in the past when they would go cycling together and how they continue to enjoy each other’s company and make the most of their situation.

Sue described issues with the changes that dementia has brought about in her mother’s personality. She describes how her own mother, who she was usually very kind and gentle, has attacked her father in the past because she didn’t recognise him:

“The other thing we did was, cos Mum’s started, every now and again she thinks that Dad is a strange man who’s trying to get rid of her which is absolutely heart-breaking. She, twice now she’s gone outside to try and get help and luckily the neighbour, well once the neighbour brought her back in the second time she came back in but then locked Dad out ... So I phoned up the doctor and said can you refer them back to the, they’re called the Older Persons Mental Health team apparently so they had an appointment with a registrar there who’s prescribed some different medication, or some medication which Dad is holding out great hope for and we’re just sort of waiting and seeing but also referral to the community mental health team because I think Dad and I both need a phone number so that if Mum does something really weird we can phone up and say what do we do? You know do we ignore her? Do we pander to her? Do we lock her up? What do we do? Cos that’s the trickiest bit at the moment ... particularly with Mum’s episodes, I mean we had the worst was four times in one week but thankfully Dad now calls me because I can go over and I can calm her

down a bit or I bring her here and just give him some space. I think he was coping on his own for a while without telling me.”

The emotional aspects of care have an impact on both the carer and the care recipient. The burden of caring for a spouse and the loss of physical abilities can be difficult to come to terms with. Penny spoke about her Grandmother’s depression and occasional difficulties in coping with caring for her husband:

“So you could tell already that the stress is hitting her. Then things ticked over, like I say, for a little while and my nan then started to become quite depressed. She started to become really really down and I think they call it carer’s stress actually. Bearing in mind they live out in the middle of nowhere ... I think there is one bus a week for an hour. You know it gives you an hour in town and then you are back up again but there was no facility for my granddad to be looked after while that bus went so unless I was up there. I can’t go up on a Friday because I work, and that’s when the bus goes, so if it was a Thursday I would go up there but one of us had to stay, I had to stay with Granddad or take Nan. It was an impossible situation.... When my Nan was poorly and feeling quite depressed she didn’t want to be at home on her own at night, with Granddad, but she got very anxious and was having panic attacks and she didn’t want to be on her own at night. Bless her, I felt so sorry for her because there was one Friday night where I’d got in from work with the boys, it was about 8 o’clock, you know, they were sorted in their pyjamas, I was cooking my dinner, had a glass of wine on the go. I’d had a glass of wine when I got a phone call from my Nan saying Pen, I can’t be up here on my own please come. So then, you know, I’d had a drink so I then phone a taxi can you be here in 10 minutes. Haul the boys out of the house with their TV under their arm in their pyjamas waiting at the end of the road and go up there. You know, what other choice did I have at that point?”

Penny positions herself as having no choice but to take her sons and go to her grandparents. Higgs and Gilleard (2015:100) suggest that caring or not caring about others implies an ‘affective’ response mediated by a moral identity and that this response includes feelings of pity, alongside sympathy and compassion. Carr (1999:428) argues that the emotions of pity and compassion can be seen as social virtues. He suggests that compassion ‘is an appreciation of the suffering as conceived by the one who suffers, whereas pity involves a grasp of the misfortune of which the sufferer is unaware’ (Carr, 1999:428). Carr (1999) suggests that compassion allows us to feel ‘with’ the other whilst pity is about feeling ‘for’ another. Penny can be seen to feel that she has no choice but to help because of her compassion, her feeling ‘with’ her grandmother, for her grandmother’s suffering.

The most powerful emotions regarding later life for the participants is that of grief. The final part of this chapter presents two participants’ narratives relating to the death of their partner. These stories were perhaps more detailed because the deaths occurred at home. Shilling (2003:163) points out that there has been a decrease in the public space afforded to death

which makes it increasingly problematic for people. Rather than being a communal event it is now a relatively hidden, private experience and the once traditional practice of keeping the body in the home for a few days before the funeral is becoming increasingly rare (Shilling, 2003:164). This means that people are socially unsupported and vulnerable when it comes to dealing with death and the details that the participants shared suggests that they welcomed the chance to speak about the experience.

Rachel had been talking to me about caring for her partner, Stefan, who died in a care home but also spoke about caring for her husband, Alan, who had died in the 1970s from cancer:

“You see when Alan died, he’d been my life and although I’d got three children ... worrying about money, how we could manage and everything but when Stefan died there was none of that, the house, this was my own, no children to worry about and oh I missed him dreadfully... , it took me ages, it took me a good twelve months after he died to feel anything like myself again ... “

Rachel cared for Alan at home and towards the end he was in a lot of pain – she spoke of a time near his death when his cancer had spread to his brain and he had a seizure at home:

“I screamed because I didn’t know what was happening and I screamed. Don’t take him, don’t take him like that, because all I could think of, the children were coming home ... I thought I can’t leave him, I can’t leave him ... fortunately I’d got my keys in my pocket, why they were in my pocket don’t ask me but they were in my pocket and I opened the bedroom window and a chap was going past and I says, called him, and I said, I don’t know who he was, a stranger and I says could you go to the house on the end please and knock on the door and get the daughter to come to my house and he looked and I says please I need her, I need her and she came and I threw the keys to him and she came and she phoned the doctor and by this time the swelling had gone and the doctor came ... and he told me then, he says, the cancer’s hit his brain. But he went all through the night and next day ... and then he died during the night.”

The story of Rachel’s husband’s death in the 1970s is very different to the story of her partner’s death thirty something years later. The death at home was not a peculiarity of the time, it still happens today. June told me about the moments leading up to her husband’s death:

“I went into him, it was teatime and I went into him because I was going to have my snack and I went into him and I went like this (shows a smoothing motion) round his face because he needed a shave and I’d got an electric razor and I hadn’t done it that day and I said Ooo look we’ll have to get you shaved. I never did like a man with beards I joked and he laughed, you know, he was quite with it and I came and I had my little snack and about quarter of an hour later I went back in and he’d died. So he didn’t have any pain and he died in his own home so I couldn’t have done anymore.”

June’s narrative portrayed an affection that left me feeling that I had been told an intimate detail of her married life. June’s assertion that her husband had not been in pain and that she

felt that she had done everything that she could for him suggested the perfect end to a care story.

Discussion

This chapter began by exploring the intersection of informal and formal care, beginning with the adjustments that the informal carers face when their relative first moves into residential care. Milligan (2003) proposed that care may be viewed as a continuum that ranges from informal care delivered within the home, through a mixture of informal and formal care delivered at home, to care delivered within institutional settings (Milligan, 2003:467). For some older people, their care involves moving along this continuum. During that time not only do the older people who have moved into formal care need the continuing support of their relatives, but those who have been informal carers need to come to terms with the changing relationship. The narratives of the participants in this research confirm Milligan's (2003) suggestion that the boundaries between informal care and formal care become blurred.

This research has found that the period around the move into the nursing home can be particularly traumatic for many relatives, involving a process of sudden adjustment to being without the older person on a day-to-day basis, as well as the need to undertake many practical tasks (Wilson, 1997:524). Relatives may seek reassurance by checking if the older person has been involved in any activities, asking about their dietary intake and appetite, and observing how care staff spoke to their relative (Wilson, 1997:522). The nature of the involvement of informal carers ranges from continuing tasks such as providing clothing to ensuring that their older relative has appropriate activities to keep them entertained. Jerry spoke of an issue with the television both when his mother was at home and when she had moved into a care home. He described how his mother had been unable to use the remote control and so he had always ensured that she had something to watch that she enjoyed. He provided the care home with a list of his mother's favourite programmes and was concerned that this was not being consulted by her carers. This showed his difficulty with letting go of the caring role that had been such a huge part of his life before his mother moved to the nursing home. Jerry was seeking to keep a connection between not only himself and his mother but also with his mother and the outside world. These continuing tasks of care illustrate how formal and informal care become entwined.

The discussion of particular experiences of the participants showed how they were faced with difficulties that appeared to stem from attempts to define care as specific tasks, actions, or

commodities that could be assigned to different care professionals. These narratives support the assertion by Hoppania and Vaittinen (2014:83) that the neoliberal attempt to commodify care is disrupted by “bodies entangled in corporeal relations of care”, bodies that continue to be cared for through relationships with other bodies.

This commodification or delineation (Mol, 2008) of care tasks can lead to the possibility of formal carers disputing their obligation to deal with or consider a specific task. This was evident in Penny’s story about her grandfather’s wound which was not considered to be within the remit of nursing staff as it was a minor problem that could be dealt with by simply washing. They did not take into account the fact that he was not able to care for the wound himself and his wife was already overwhelmed with other tasks.

The additional problem with dealing with care issues without considering other needs was that participants described being treated as “an ailment rather than a person”. As Stange (2009:102) points out, the advances in medicine derive from a focus on a particular problem and this leads to a fragmentation as health professionals focus on their speciality without appreciating its relation to the whole person. He suggests that this fragmentation leads to “inefficiency, ineffectiveness, depersonalisation and discord” (Stange, 2009:102).

Andy described being made to feel like an “item of information” and that sourcing medical equipment that he needed for his recovery from an operation involved being passed around several departments with no clear pathway in which to obtain the item that he needed. This echoes Peel and Harding’s (2013) study where their participants described negotiating health and social care services as “a terrible maze”.

The narratives in this chapter included one participant being discharged after a heart attack despite being the carer for her husband with advanced Parkinson’s disease and another participant needing to arrange for a doctor to undertake a review of her mother’s care to ensure that there was an overall view of her condition. These stories show how the commodification of care leads to a focus on a particular problem, symptom or illness and the context in which care recipients exist is often not considered. For the individual care recipient, their situation in life, their social supports as well as their responsibilities are an important part of their identity. By reducing them to a single illness or care task leads to a dehumanisation of the individual and a feeling that they are not being ‘cared for’ by those undertaking formal care.

The blurred boundaries of responsibility between informal and formal care were explored further through narratives of medication. The management of medication for those in short term residential care was seen to be problematic, with the communication between the care home and the informal carer sporadic. Penny's narrative describes the difficulty of continuity of medication when people are placed in nursing homes for respite care. The responsibility of medication appears to be a grey area between informal and formal care. These difficulties in arranging the medication for family members who are in care homes for respite or short term care appear to be unexpected. It would be reasonable to assume that the care homes would have systems in place to ensure that prescriptions can be filled and that medication is given continuously and so avoid the risks that any break or lack of medication may entail.

Medications are an important aspect of daily life for older people as medical problems can increase with age and a variety of medication may need to be administered (Duerden & Payne, 2013). Taking medication can be seen as the practice of self-care, in this sense 'practice' can be taken to mean something that is undertaken frequently (Morgan, 2013:6). The importance of medication was described by several participants. Andy was responsible for monitoring his wife's medication which had to be administered every two hours and Mrs Cole was responsible for administering her husband's medication which had to be given every four hours. They were aware that there would be problems if the medication was not given on time but were not clear about what those problems would be. This emphasis on the timing of medications places a high level of responsibility on the informal carer which together with the very intrusive nature of two or four hourly dosage made the medication a prominent feature of daily life.

The adherence to a medication routine links to what Foucault (1988) called 'technologies of the self', the practices that individuals undertake themselves, not because they are subject to an external force but because they believe it is in their best interests, having internalised the norms that have been established (Howson, 2013:158). By taking medication the participants are continuing to respond to the public health discourse that encourages individuals to observe and monitor their own health (Howson, 2013:158). In addition this activity of managing medication would be termed an 'ascetic practice', an art or technique learned by practice (Heyes, 2006:139). Such repeated practices are considered a "necessary condition of effective citizenship and relationships. We owe it to ourselves and to others to constitute ourselves as ethical agents through ascetic practices" (Heyes, 2006:139).

The semi-structured approach to interviews allowed participants to identify the elements of care that they considered to be important providing narratives on aspects of care that would not have been included within a more structured approach to data collection. The connection between food and care was seen as an important issue for informal carers as well as those being cared for. The link between food and agency was touched upon through the identification of inflexibility on the part of both residential care homes and hospitals. This led to distress for both informal care givers and care recipients.

In considering food and its connection to care, the nutritional value is not the only aspect to 'nourishing care' (Mol, 2010:217). Mol (2010) explores how it is not only the substance of food that deserves attention but how the practice of eating is at least as important and, in that context, 'cosiness' or comfortable surroundings play an important role. Jerry spoke about the disappointment in the food arrangements at the care home where his mother was living. Jerry made a point about the food and crockery being aspects that could be personalised to suit individuals but instead appear to be operated on a minimal cost basis

Diet and the discipline of eating well are also associated with technologies of the self (Foucault 1988). Rose (1996:129) identified three ways of relating to the self: epistemologically (knowing yourself), despotically (mastering yourself) and attentively (caring for yourself) each of which is a different kind of technology of the self. By denying Jerry's mother the agency to determine when and what she eats, it could be argued that she is denied the power to care for herself and to master herself. In particular, Jerry's mother had always had tea in a bone china cup and for her to drink from a thick rimmed mug was, for Jerry, a way of diminishing the pleasure of a comforting cup of tea.

For June, preparing food that her husband enjoyed was not only a part of care it was also an act that was strongly linked to emotion because it was a fundamental part of the way that she cared for her husband. She spoke about her problems with the hospital food as an example of a time that she cried. This was the only time she spoke of being upset in this way. Food can be seen as a way of 'doing family' (Finch, 2007) and it appears important to carers that they not only show that they are 'doing' care through the provision of healthy and nutritious food but also that the people that they care about are getting pleasure and satisfaction from what they eat. Daily life practices such as eating, rather than just being more or less pleasant on their own terms, are essential for physical well-being as "eating bodies and the practices of eating make each other be" (Mol, 2010:218). Good food and 'nourishing care' can lead to pleasurable experiences in daily life.

Finally, the chapter explored emotions in later life by collating narratives where participants spoke of the difficulty in coming to terms with illnesses and loss. These narratives emphasise that emotions in later life are experienced in a similar way to those at other points in the life course, participants describe feeling the same as they did in their teens. The deaths described here happened in the home and are not viewed as a failure of the care giver but rather as an appropriate end to the care journey.

Exploring care as a relational process provides insights into the ways that care activities are impacted by relationships between care recipients and the world around them. The narratives presented here suggest that examining care activities improves our understanding of choice in later life and shows that choice continues to be important to older people. Rather than a focus on choice over care provider it is control over the ways in which care activities are carried out that is valued. By examining the way that the concept of choice relates to the practice of caring, it can be seen that the shared understandings between family members and older people provide a way for older people to express preferences that they might otherwise find difficult to convey.

Chapter Seven: Discussion and Conclusion

Discussion

This thesis sought to understand how the concepts of care and choice are enacted, experienced and interrelated in the context of both informal and formal care in later life and how older people themselves, their families and significant others understand and experience these concepts.

The research began by considering the way in which older people, family members and significant others were involved in making choices about care. The research was underpinned by a Feminist Foucauldian theoretical perspective that provided the scope to explore gender assumptions and power imbalances within care relationships. The feminist perspective adopts the view that the knowledge of individuals, both that of the researcher and the participants, are partial views of the world that are both limited and embodied. The Feminist Foucauldian perspective provides a framework for examining the disciplinary practices by which ageing bodies are subjected to the effects of power, in particular the power of the social imaginary of the Fourth Age whereby older people are constructed as frail, abject and powerless. The research drew on insights from Tronto's (1993) feminist ethic of care that emphasises the viewpoint of both the care giver and the care recipient. It is from this perspective that the thesis sought to answer the questions of how older people, their families and significant others understand care and choice in later life and how the policy emphasis on individual choice impacts on decisions relating to formal care in later life.

The following discussion sets out the key contributions of this work to theoretical understandings of older people's care experiences. Representations of care often use the metaphor of a journey to describe the way in which care is negotiated. In particular, 'caringscapes' (Bowlby et al, 2010) offers an image of a hike through a rural landscape, whereas Peel and Harding (2013) suggest a journey through a maze, portraying the difficult and uncertain aspects of the journey. The narratives presented in this thesis argue for an addition to these images to allow for the inclusion of hills and valleys in the care journey. The increase in needs that arise in later life could be regarded as hills to be climbed. As needs increase they become more visible. This view of care needs as undulating highlights the fact that there is no point in the life course when we have no need for care, even if that is taking care of ourselves. As care needs increase there may be a gentle incline or a difficult uphill struggle; at the peak of the hill our need for care becomes more visible. For older people who

experience a short illness the first need for additional support could be viewed as the first 'bump in the road'.

Journeys of care are not undertaken alone; older people experience care, both informal and formal, as a relational activity. Participants spoke about 'helping' others rather than 'caring' for them, even when undertaking tasks which would be identified as care work if undertaken by a formal care worker, tasks such as lifting someone off the commode or helping them to brush their teeth. For some, the change from traditional kin and partnership relationships to those of carer and care recipient arise as a result of an illness or fall, but for others the transformation happens through gradual, imperceptible changes. For many, this evolution involves visiting a relative or friend a little bit more often, and taking on additional tasks in the home. These small adjustments to everyday life often allow for help to be offered and accepted without any explicit discussion and, as such, the individuals might not identify themselves as either 'carer' or 'care recipient'. 'Tinkering' with tasks is very much the nature of care that is described by Mol (2008), where adjustments are made to everyday routines to determine what brings improvement and what does not. As the carer becomes more and more entwined in the life of the care recipient the relational aspects of care become more significant. There is a development of a common and, crucially, a relational understanding of the needs and preferences of the older person, the informal carer is acutely aware of what has worked in the past and what has not.

The evolution of care roles within families is interwoven with the process of negotiation described by Finch and Mason (1993). The long history of gendered assumptions about women as 'natural' carers continues to impact on care relationships. There are no strict rules about who should provide care within families and Finch and Mason (1993) argue that care provision is not solely based on obligation or reciprocity. Instead, care responsibilities are negotiated and the previous quality of the familial relationship may influence the willingness of an individual to offer care. Finch and Mason (1993) suggest that a refusal to adopt a care role is often framed as an inability to undertake the role rather than an individual being unwilling. Each negotiation begins with an acknowledgement that proximity is an important factor, particularly when hands-on care is required (Phillips, 2007:112), to be able to help they need to be local and available. Where more than one family member is living nearby, negotiations about who will or will not do the extra work hinge on an individual having a 'legitimate excuse', a reason not to provide care which is accepted as legitimate by the care recipient, rather than by any other family member. There is an understanding that excuses

relating to being 'unable to care' rather than 'unwilling to care' are more readily accepted. However there are exceptions; an individual may declare that the history of the relationship is a reason to refuse a care role.

Whilst it may be difficult for people to assert an unwillingness to care, it appears more acceptable to report an inability to care as an older person's care needs increase. Informal care relationships were often framed by participants as one informal carer undertaking the majority of care tasks. As the older person's needs increase, so do the demands on informal carers until a point is reached where outside support is sought. This limit to informal care was often linked to problems with mobility and the need to assist the older person with toileting. This aspect of care is both emotionally and physically demanding for the informal carer, although it is often the physical demands that are described as marking the limits of informal care.

The aim of informal care, as described by care givers, is to maintain the care recipient's sense of well-being, to ensure that they feel cared for. Well-being is possible even in ill health and deep old age and involves a focus on the positives rather than deficits (Galvin & Todres, 2013). The narratives of the participants suggest a 'preservation of identity' that extends Grenier's (2012) discussion of the continuity of work and leisure activities to the continuation of life long habits that are part of the small details of everyday life.

Care in later life involves the practices of keeping the older person as comfortable as possible as well as maintaining their identity through the continuation of practices that link to their personal preferences, for example their taste in entertainment and food. These are important aspects of exercising choice in order to maintain identity through the continuation of past habits, the details that not only make life more comfortable but which constitute individuality. These elements of individuality do not require vast resources or widely different approaches but rather an attention to detail that is possible within care relationships that focus on the communication of shared meanings between the care giver and care recipient.

The notion that emotions are experienced in the same way in later life as they are in earlier points in the lifecourse is an important aspect to understanding experiences of care. It does not get any easier to accept the intrusion of others into our personal space; this challenges the individual's sense of independence and competence regardless of age. Negotiations around informal care involved not only consideration of who would undertake the care role but which care tasks people were willing to accept that they needed help with. Attention to the

relational nature of care brings to light the emotional work involved in care. The emotional work of carers has been widely discussed in academic literature (Twigg 2000; Ungerson 2005) but the emotional work of the care recipient is shown in this thesis as being equally important to the quality of care that is provided.

Negotiations surrounding the provision of care within families may unfold differently depending upon the relationship involved. As these care relationships often evolve without explicit discussion of the arrangements being made, there may be different expectations of that relationship. For example, a care recipient may assume that relatives can continue to provide care, whereas the relatives' health or strength may preclude that. When the demands of informal care increase, relatives may seek to put more formal care arrangements in place as a preventative measure rather than deal with a crisis situation that they see looming on the horizon.

The narratives described difficulties in the attempts to introduce formal care into the homes of older couples. A couple's experience of care is a shared experience as they both have to accommodate strangers coming into their home and becoming involved in their personal routines. Some participants described how informal carers sought to adopt techniques of 'passive resistance', through which an individual acts in a manner that bypasses direct confrontation, but nevertheless achieves desired outcomes (Lorentzen, 2008:74). Whilst some participants viewed the introduction of formal care as intrusive and disempowering, others saw it as a necessity that enabled them, or the person they cared for, to remain in their own home. Managing formal carers is an important element of continuing care in the informal setting of the home. Preferences regarding care workers are linked not only to their ability to undertake emotion work but also to the care workers' age with older care recipients suggesting that they are more comfortable with people closer to their own ages.

The narratives offered by the participants suggest that the move from informal to formal care does not necessarily lead to an immediate cessation of informal care. Not only do the older people who have moved into formal care need the continuing support of their relatives, but those who have been informal carers need to come to terms with the changing relationship. The exploration of the interaction between informal and formal care has shown that the boundaries between the two are not clear cut. Once formal care has been arranged, informal care continues as family members seek to add to the formal care and continue with some of the care tasks that they important for the quality of life of the person that they care about.

This continuation of care emphasizes the importance of considering the context in which older people's care is provided.

In policy discussions of care in later life, choice is considered to be a way of ensuring that older people have control over their care and there is an assumption that the choice will be made by the older person themselves. How the decision regarding the nature of formal care arrangements varies between families and the timing of it depends on the rate at which the older person's care needs change. Often the older person appears not to be involved in the choice of formal care, not due to a paternalistic attempt to exclude them but because relatives are seeking to protect the older person from the effort involved in making a choice, or because the older person is unwilling to consider the options, perhaps denying the need for formal care.

Both in academic literature and in the participants' narratives presented here, relational care adapts and adjusts to care needs, and compassion plays an important role in understanding the nature of choice. Compassion in care is very different to the notion of obligation. We may feel obliged to care for another person without any understanding of that person's feelings or experiences. By perceiving compassion as a feeling 'with' another, an awareness of how it feels to experience suffering, we can understand how those who undertake the role of informal carer may feel that they have no choice but to provide help.

The discourse of choice is so pervasive that statements of 'no choice' in care are difficult to articulate. Yet by exploring choice we find that such situations do exist and are linked to ideas of 'feeling with' the care recipient. The feelings of 'no choice' but to provide care and 'no choice' but to cease the care role are strongly associated with the relational nature of care and associated compassion.

In situations where decisions regarding formal residential care needed to be made, a clear difference between careful consideration of options and crisis situations was evident within the narratives of the participants. Whilst having the choice of care provider is described in policy as providing opportunities for empowerment, the narratives here show that choice of provider is not the main concern for older people and their carers. Although the participants did want friendly, age-appropriate carers or a local good quality care home, the elements that were most important were the details that help to preserve or maintain identity. Older people can continue to influence the nature of the care they receive if those around them are attentive to the ways in which they indicate their wants and needs. An understanding of

preferences may be achieved by drawing on the knowledge of those who have previously cared for the older person or from families and significant others who have shared experiences and are seeking to preserve those practices that the older person has used in the past to maintain their identity.

In discussing particular practices of care it is possible to identify specific situations in which individuals are enabled or prevented from exercising choice. An example is in the provision of food, which plays an important role in care, both care of others and care of the self. Again this is an aspect of life that is problematic throughout the lifecourse not just in later life, as shown in the extensive discussions around diet and care of the self in feminist writings. For older people, food tastes and habits have developed over the lifecourse and so to go from always having an evening meal and a light lunch to having a main meal at lunchtime and a light supper may lead to a sense of incongruity with the past. For those who are caring for partners, the provision of food may have played a part in their relationship and to have that role removed can be difficult to come to terms with. By denying an individual the choice of when and what they eat, it could be argued that they are denied the power to care for themselves and to undertake the techniques of the self that shape and maintain individual identity.

In considering food and its connection to care, the nutritional value is not the only aspect to 'nourishing care' (Mol, 2010:217). Mol (2010) explores how it is not only the substance of food that deserves attention but how the practice of eating is at least as important and, in that context, 'cosiness' or comfortable surroundings play an important role. Daily life practices such as eating, rather than just being more or less pleasant on their own terms, are essential for physical well-being as "eating bodies and the practices of eating make each other be" (Mol, 2010:218). Good food and 'nourishing care' can lead to pleasurable experiences in daily life.

In modern western societies, social policy is influenced by neoliberal ideas of individual responsibility and personal choice and this has led to attempts to commodify care through the delineation of care tasks and care becomes a 'product' that changes hands (Mol, 2008:21). This can contribute to situations where providers of formal care dispute their obligation to deal with or consider a specific task. From the perspective of the care recipient, this leads to a sense of dehumanisation and a lack of understanding of the context in which their care needs are situated. Interaction with care professionals can lead to care recipients being considered in terms of their isolated symptoms or problems. In these situations power relations become

increasingly important as older people express difficulty in challenging medical knowledge and power as discussed in the narratives of interacting with care professionals.

The personalisation agenda aims to move towards a greater emphasis on individual choice and personal responsibility and this is reflected in the funding structure with fewer people being eligible for state support and greater numbers being expected to self-fund their care. This leads to concerns over the way in which future care will be paid for and how care arrangements may have to change to reflect dwindling resources. The concerns over funding contribute to the experience of care in later life as being a time of instability.

By tracing the evolution of care relationships through the peaks and troughs of the care journey, I have sought to emphasise that when considering the notion of choice we need to allow for and acknowledge situations of 'no choice'. These situations arise through understanding the needs of the care recipient and placing them above the needs or wants of their family or significant other. The relational aspect to care, the 'feeling with' the care recipient can also help to preserve individual identity through the communication of preferences and the continuation of habits of daily life.

Methodological Reflections

Drawing on a feminist Foucauldian theoretical approach, a research methodology was selected that would ground the research in the experience of the participants with an awareness of the socially and historically located nature of their narratives and my own influence on the direction of the research. The adoption of an unstructured approach to face-to-face interviews stemmed from an initial focus group study. This group discussion indicated that people wanted to talk about the situation in which care choices were made and that each situation had its own particular challenges. The participants in the subsequent interviews were asked to 'tell me about' their experience of care and were free to describe what they considered care to be and to include any narrative detail that they felt appropriate and important. This led to narratives on topics that had not been considered prior to the interviews such as the importance of the food. The Foucauldian underpinning of the research allowed attention to focus on the way in which power relations impacted on the experience of the participants. The method of analysis was dialogical narrative analysis, a method which seeks to collect people's stories and to re-tell them for others to hear. There was no intention to provide a solution to the challenges of care in later life but the aim of using dialogical narrative analysis was to allow the stories to be heard beyond the private realm of the family. The interrogation of the narratives allows for an understanding of the way in which choice and

agency are entwined in the experience of care in everyday life. These understandings are lacking in the literature and in policy, which assumes a particular articulation of these concepts whereby good care is understood to follow automatically from individuals making definitive choices.

Limitations and Future Research Directions

This study focused on older people with stable informal support networks, particularly family and friends living nearby who were able to adapt to their changing needs on a daily basis. For older people who do not have local informal support networks, their experiences are likely to be vastly different. The difficulty in reaching this marginalised group was encountered when trying to recruit for this project. Many participants were recruited through family and attempts to recruit through care providers proved problematic.

Future research would usefully further explore the relationship between informal and formal carers from the perspective of relational autonomy and how the shared understandings of informal carers and care recipients could enhance the relations between care recipients and formal carers. The family structures explored here were traditional, raising the question of whether future research could explore the way that structural forces might impact on care givers and care recipients within same-sex relationships and children caring for same-sex parents.

Implications for Policy in UK and Overseas Contexts

The findings show that there is a contrast between older people's emphasis on relational care and the option to make the choice not to receive care and the social policy discourse of empowerment for older people through individual choices.

The narratives demonstrate that there are limits to informal care. These limits appear to relate to being unable to provide care rather than be unwilling to continue the care role. Informal carers will continue to carry out their care roles even when this is having an impact on their own health. Whilst social policy is increasingly aware of the importance of the role of informal carers, there should perhaps be an emphasis upon supporting their care role in ways that are meaningful to them rather than providing formal care workers to take over specific tasks.

The narratives portray a relational care that adapted and changed as the needs of the older person changed. Informal carers sought to 'keep' the care recipient well, keeping them clean

and content and also helping them keep their identity. The interaction with formal carers working to support informal carers within the home provided important insights. In particular, the impact of care workers with whom the care recipient was uncomfortable. This raises the question of whether the choice of specific carers could be an option that is more easily available to care recipients.

Final Thoughts

I have learnt so much since beginning this project, not only in terms of academic understandings but in respect of the process of research and, in particular my concerns over the intrusion into the lives of care givers and care recipients. At the time of the fieldwork, I felt that I was taking away the participants' time and delving into their private lives, but I now understand and appreciate that they actually welcomed the opportunity to tell their stories and were able to steer me away from any narrative that they did not wish to share. I am very grateful to the participants who were willing to share their stories with me and I hope that my representations have done justice to their experiences.

The key original contribution of this thesis is that it disentangles the concepts of care and choice that have become so rigidly articulated in discourse. In doing so, the thesis thinks about these differently through considering what older people, their families and significant others consider care to be and the extent to which the language of choice is relevant to their experiences.

The language of choice assumes that opportunities for choice by care recipients will lead to improved care. This thesis argues that the relational nature of discussions of care in later life must consider not only older people but also those who are impacted by care choices, whether they be spouses, informal carers, family members or significant others. The narratives add to the discussions of care as an activity that requires constant re-configuring and attempts to frame care as a single 'choice' bears little connection to the everyday experiences of older care recipients. I have argued that we need to allow for, and acknowledge, situations of 'no choice' that come about through compassion and 'feeling with' the care recipient.

It is not possible to think of care in the individualistic terms of policy discourse. Informal care is negotiated between individuals, often not explicitly but through casual conversations about the management of specific tasks. In this context, the language of choice does not appear to be one that is appropriate or relevant to the older person in need of care. In situations of

formal care, older people speak of being 'put' into a nursing home rather than choosing to go into one.

In understanding the experiences of 'real' old age, the concepts of care and choice need to be explored in the context of the social networks within which they function. By considering the relational aspects of care and choice the identities of older people may be maintained, their preferences and needs understood through the common understandings they share with those around them.

Relational understandings of care emphasise identity preservation by continuing to support the preferences of the care recipient in the details of everyday life. Such preservation of identity does not require active participation by the older person but a willingness to respond to any indication of preferences articulated by language or other means, or even through relatives. The notion of choice has been examined as a distinct concept rather than assuming an inseparable connection with care thus enabling an exploration of the way that care relationships advance or constrain older people's opportunities to make choices.

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